

# **A Practical Guide to Potty Training Your Child with Down Syndrome Before Age 5**

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## **Acknowledgments**

To my former, present, and future students.

## **Forward**

**As a mom of a child with Down syndrome. I know the desire to do everything you can, to help them reach their full potential. Often along that journey you seek out allies - other parents, professionals, and teachers to help along the way and hope that they can see the potential we see in our child. Sometimes, these professionals want to caution us to not get our hopes up, or automatically just point out deficits. If we are lucky, we meet professionals who see what we see and more in our child.**

**When my son was about 8 or 9 we had an opportunity to drive 45 minutes one way to do tutoring with Little Leaf, in collaboration with DSA of the Midlands. It was well worth the travel to have this opportunity and to work with Kim from Little Leaf. After the program ended, we continued private tutoring at Little Leaf.**

**It was evident to me from the beginning, not only did Kim see the value of kids with Down syndrome, but she could also see their potential, and knew how to draw from them some of their best efforts.**

**As a parent who attends many conferences and webinars to continue to learn about Down syndrome and what it will mean for my son, I have heard a lot of experts speak. Some were good, some were not, and a few were great. Right there on my great list sits Kim. Up until now, families and children with Down syndrome in the Omaha, Nebraska area have been the main recipients of her expertise and knowledge. I am so excited that this book will give many more families access to her insightful and innovative practices and ideas. I have no doubt that if families follow this approach, they will potty train their child earlier and improve future outcomes for themselves and their child.**

**Angie Willey,**

**Mom to Ben, age 13**

**Advanced Signing Time Instructor.**

## **Introduction**

Let me take you on a journey of a willing heart, determination, small steps, and patience that led to a life-changing potty training program. Because my students have all of these qualities in abundance, today I can share with you how so many children with Down syndrome have been potty trained before starting Kindergarten.

## **Chapter 1**

### **The Journey**

Our journey began years ago in our early intervention classroom for children with Down syndrome ages 18 months to 6 years. Our classes are four hours a day, with six to eight students in each class. This environment allowed me to find patterns and common issues around potty training for children with Down syndrome.

I want to give you a bit of background to understand what led to my mindset on potty training. In my first years of running Little Leaf, the same scenario played out time and time again with family after family.

An expert would present about potty training or the latest book on the topic was released. Parents were excited to get the information. The information motivated parents to potty train their children. They were geared up! They had rewards, potty watches, visual timers, favorite character underwear, parents would take dedicated time off work, or plan to potty train over a holiday break. It is game on! They are excited, and I am excited for them! So the next time the child comes to Little Leaf, I expect them to be wearing underwear. But this never happened. So why did so many families fail at potty training?

Well, after many conversations with parents that went a lot like this:

**Mom:** *"I don't think Max is ready to be potty trained."*

**Me:** *"Why?"*

**Mom:** *"He would go on the potty, then ten minutes later he would have a little accident. He was having little accidents every 10 minutes all day long."*

Two common threads emerged: one, my child must not be ready, and two, the child goes little bits in between going on the potty chair.

After hearing the same thing from so many parents, I start to wonder. How could this be? Everyone is going a little tiny bit every ten minutes? I don't change their pull-ups every ten minutes. I started checking pull-ups every ten minutes, dry, I would think, why would they be going every ten minutes in underwear?

*\* It is not that kids only go a small amount. They do go larger amounts too. The small amounts are more like leaks from the bladder. Can any of you "moms" relate?*

What to do? Well, I did what I always do: pray, meditate, read, read, and then read some more. After all that praying, meditating, and reading, I had a gnawing question. Could kids with Down syndrome have a weak bladder? Could that be the cause of all those little accidents (leaks)? I reached out to medical professionals and got no response. I read a few studies that briefly touched on hypotonia's effects on the bladder and other muscles involved in "going potty." If my theory was correct, we could find a way to help; a weak bladder can be strengthened. But, even if it can be done, I have no idea how to teach pelvic floor exercises. Let alone teach them to toddlers. Pelvic floor exercises aside, the only way I can help is to start potty training with my kids at Little Leaf.

I got underwear for all the kids, put them on, and got started. I planned to put underwear on all the kids so I would know exactly when they went potty. Most of the kids ARE going little bits every ten to twenty minutes. Really! Everyone is going a little bit every 10 - 20 minutes, just like so many parents said their child was doing. To experience it with so many kids proved to me that a different potty training approach might be needed for children with Down syndrome(Ds).

I am becoming more convinced that potty training has not been successful for some physical reason. Perhaps our kids are not ready for an intensive one weekend, throw out the pull-up kind of thing. I suspect that their body might need a little help to be "ready" to potty train. I am convinced cognitively they understand. I do not believe cognition is causing the delay in potty training.

*"Will their body just be ready one day?"* I don't know, so I pray, meditate, and read. According to parent reports and data for children with Ds that I can find, this does not seem to be the case. What is becoming apparent is if a child with Ds goes into kindergarten unpotty trained, they will likely not be potty trained until they are 7 - 8 years old. Our students and their bodies need specialized intervention to hit so many milestones. Do kids with Ds need specialized interventions for potty training? Why is potty training treated differently?

Okay, back to everyone peeing all the time. Here I am with six kids with Ds all needing new undies every ten to twenty minutes; no way this will work. I have to develop a new plan because I am determined these kids are going to get potty trained! I aimed to keep my sanity.

Thoughts battle in my head. *"We won't get anything done if we are in the bathroom all day."* and quickly the next thought was *"Being potty trained is huge!"* This is the kind of thing that makes a lasting impact on someone's life. Does potty training have to mean getting rid of the pull-up? Can we practice using the potty chair and continue to wear a pull-up? We can do this! Fingers crossed, I prayed, and the kids went potty, potty, potty. I decided that yes, we could practice and still wear a pull-up. I chose to look at this as decreasing the support needed, just like when a child learns to walk.

Everyone is back in pull-ups. Everyone is going on the potty chair! Time to celebrate? Not quite yet, we are using the potty chair every 20 - 40 minutes, but it is just a tiny amount, about a quarter's size. *"That can't be right?"* Our kids are pretty big, and I

know how much they had to drink this morning. My mind went back to the question: could the bladder and muscles used for going potty be weak? Maybe? But whatever it is causing them to have small accidents so frequently needs to change. Going potty every 20 - 40 minutes is too much if we want a life outside the bathroom.

*"We need to focus on fully eliminating the bladder."* How do we do that? I have no idea. I need some advice from someone in the medical field, a urologist, or a physical therapist, or an occupational therapist.

As fate would have it, one evening while socializing at my husband's work party I met an OT. She mentioned that many of her clients had urinary incontinence. Well, well, I could not get any medical professional to respond to my phone calls or emails. I had an OT who works with women to strengthen their bladders and she has had a couple of cocktails. Right there in front of me. *"Praise be!"* So, with a little liquid courage, I told her my experience and my theory that children with Ds may be having urinary incontinence too. She seemed intrigued, she did not look at me like I am crazy; she even gave me a little advice. Her advice was to have the kid blow, so I got horns, pinwheels, and bubbles. If you can blow it, I got it! What she really gave me was encouragement; my theory made sense to her too. Our kids needed to strengthen their bladders and muscles for going potty. They needed to practice going potty so that their bodies would respond quickly. I decided to run with the assumption that many kids with Ds have urinary incontinence. I planned to approach potty training as a physical need, not a behavior or cognitive issue. I would help them meet this milestone by supporting what I think are physical needs: building strength and practicing going on the potty chair. How do we do that? Maybe I could just ask the kids to empty their bladders?

Okay, it is not quite that simple. Essentially, that is what I do. After the initial tiny tinkling, I say, *"go more."* When given time, usually another 2 - 3 minutes, they *"go more."* I soon realized I could say *"go more"* two more times after the first tiny tinkling.

Our goal becomes three tiny tinkles with a 2 -3 minutes rest in-between each potty staying on the potty chair the whole time. The kids could "go more" each time I ask. Now when I looked in the potty chair, the amount of urine looked like it belonged to a child, not a tiny mouse. So maybe my method was not too scientific. But now, I am convinced we are making progress.

*\*Do not celebrate too much after the 1st little potty. You don't want your child to think they are done. Instead, wait until they have gone one or two more times.*

I needed to put the kids back into underwear to see if everyone stays dry for an hour after using the potty chair. Does more output equal a longer dry time? Or will they still go a tiny bit every ten minutes? Remember, it is hard to tell in a pull-up, and the yellow stripe does not turn blue. So really, I need them in underwear to be sure. With the underwear experiment, I found out that none of the kids are going tiny bits every 10 minutes anymore. Still, they are not making it an hour either. It is closer to 45 minutes, that's better! Back to pull-ups, I had the information I needed. (I did this with many students for over two years.) Now we can wait 45 minutes. But hey! That is better! After about a month of this "go more" process, the kids start to go faster. They do not need to sit as long between the tiny tinkles on the potty chairs, and the volume of the potty is much more. Eventually, I do not need to say "go more." They do this on their own. Everyone gets faster, but we are still spending a lot of time sitting on the potty chair. We need to speed this process up.

Now the issue of their stream becomes the focus. "*Keep on going, keep on going, keep on going;*" sung to the tune of "keep on swimming" from the movie Nemo becomes our mantra. Remember all those blowing toys? It is time to pull them out. I ask kids to blow right after they initiate urinating. Blowing seems to help stretch the duration and strength of the steam. I have no idea what is happening inside their bodies. Are these interventions building control of the potty process? I cannot say whether the changes

are happening in their body or from our focus on using the potty chair, but it is working! After a month of "keep on going," the bathroom breaks became much quicker. We are in and out in 10 - 15 minutes. We can have a life outside the bathroom again! We now have a new classroom routine to include bathroom breaks, but can start to focus on other things too.

\*Boys seem to need this keep on going stage more and longer than the girls.

We have a system that is working. Now is the time to start working on potty training at home. We have developed a program that parents can successfully follow at home.

Frustration has been enemy number one to potty training success for so many families. The typical potty training advice hasn't worked. What they have tried before did not work. Methods used for siblings have not worked. Could this process be the solution parents and kids need? Together we developed a stress-free or at least less stressful approach to potty training. It is not fast. It is successful. Our families know how to take it slow, with a willing heart, determination, small steps, and patience. They have hit so many other milestones this way.

Everyone is so successful in potty training! It is just part of our daily routine. With thorough checks of the pull-ups, I find the kids stayed dry between the bathroom breaks. Bathroom trips are less frequent, and sometimes the kids tell me they need to go potty. I think *"we are ready for underwear"* This time around, I am more strategic about who wears underwear. I will choose one or two kids at a time. The plan is to change into underwear when they get to class and stay in them for the four-hour class.

Parents will choose a time at home when kids can be in their undies. Maybe a few hours on Saturday mornings to start. Then parents will keep finding more times their child can be in undies until they feel confident to switch from pull-ups to underwear.

After the switch, they wear underwear at home and everywhere else, and the pull-ups get thrown away. *And they all live dryly ever after.*

This story was highly simplified. All the tiny nuances needed to consider for each child would have made it impossible to tell you a cohesive story. Now that you know our story, In the following chapters, I will address some of those nuances and break it down into practical steps for a stress-free and successful way to potty train your child. I will also give you some updates to research that has been done since I decided to take matters into my own hands. I will explain what the research means for potty training your child.

## Chapter 2

### Practical Steps to Potty Training

#### **Step 1. Set yourself up for success.**

Check your child's diaper more often for a week or two. Note down the times that your child is wet or poopy. Watch your child closely for any "tells" signs that your child needs to go or is going.

#### **Step 2. Getting the right stuff.**

Get a potty chair that sits on the floor. Make sure it has a high back and sides that slightly wrap around your child. The right chair is extremely important to the potty training process. When going potty, your child needs to be in the best ergonomic position for toileting. A potty chair that is very supportive allows children to relax the muscles that need to relax and contract the ones that need to contract to urinate. Using all their muscles to stay upright on the potty chair will make it hard to relax and go.

Get a small table/chair that will slide over your child's legs. Use the table as a place to set the tablet and a place for your child's hands. Learning to put their hands on the table will help to keep little hands out of the potty chair and the mess inside it.

#### **Step 3. Get started.**

Using the data from diaper changes, Choose one or more times a day to put your child on the potty chair. (At Little Leaf, we start with two times per four-hour class.) You will want to have them sit five to ten minutes before the time you think they may need to go. You will need to allow your child to sit on the potty chair for 20 to 30 minutes.

I have found that after -morning snack is a good time for most of our students. Other good times to try are first thing in the morning, especially if they wake up dry. Five to ten minutes after lunch/dinner. Before bath or before bed.

Use a tv, or tablet with a video like Leapfrog Letter Factory. We have not had as much success with learning games or YouTube videos. So, now we only use shows like Preschool Prep or LeapFrog videos, and a very nice side effect is our students learn letter sound and so much more from using the video over and over. Choose something that will keep your child sitting but not so exciting they do not relax. They may spend a

lot of time on the potty chair initially, so an educational video is best. It is likely your child will need to sit for twenty to thirty minutes in the beginning.

Your child may potty right after you take them off the potty chair the first few times, keep trying until they go. This may take some time. Play around with the times you have your child sit on the potty chair. If you find a time that works well, try to commit to that time every day.

Suppose you can not find a time that works for your child to go potty. Give your child at least 8 oz of a favorite drink, then have them sit on the potty chair six to eight minutes after they have finished the drink. Or have them drink their favorite drink while sitting on the potty chair. This may work better if it takes your child needs more than 20 minutes to drink 8 oz.

\*my child will not sit on the potty. He/she is scared of it. See below at the end of this chapter.

\*my child will only sit for a few seconds. See below at the end of this chapter.

#### **Step 4. Keep it positive.**

Praise your child, “good trying,” “good sitting,” good job going potty!” Keep it positive, don't get frustrated if they don't go on the potty right away. Right now, the objective is to give your child the chance to go. As long as you consistently give them opportunities to go, they will eventually go potty on the potty chair.

\* Steps 3 & 4 may be the steps that take the most patience and perseverance. Keep thinking positive your child will go on the potty chair.

#### **Step 5. Build the brain-body connection.**

Your child goes potty on the potty chair- yay! It's likely your child may only go a tiny bit in the potty chair. If your child sat for ten or more minutes, take them off the potty chair, show them the potty in the potty chair and tell them “you went potty in the potty! way to go!” If they sat less than ten minutes, don't say anything; give a bit more time to see if they will go more. After ten minutes, take them off the potty chair, show them the potty in the potty chair, tell them “you went potty in the potty- way to go!” If your child has not gone in the first 10 minutes give them up to 30 minutes to go before you take them off the potty chair.

It is very exciting the first time your child goes on the potty chair. Do not celebrate while they are going. This can startle your child and stop the flow. Do celebrate after they are finished!

### **Step 6. Increase the opportunities to go.**

Keep up the good work and have your child go potty on the potty chair at least once a day when possible at the same time each day. Your child will probably be going just a little bit at a time. And it might take ten or more minutes for your child to go. As the brain-body connection gets stronger, it will take less and less time for your child to go.

This step takes most of our students about three months. Now is a good time to find more opportunities for your child to use the toilet. It may go faster if your child has more opportunities to go potty during the day.

### **Step 7. Focus on fully eliminating the bladder.**

Now that your child is going potty faster, it is time to go more. After the first little potty, you say, “*good job go more,*” ask her/him to go more two more times.

So, after the first potty, you ask her/him to “*go more.*”

Wait for another two to three minutes, and say “*go more*” one more time.

Do this every time your child uses the toilet. Eventually, with support, your child will fully eliminate her bladder.

The potty chair should visibly have more potty in it.

Once they can eliminate fully, the amount of time they stay dry will increase.

You will continue on this step until your child starts to fully eliminate without verbal cues and without the need to go, stop, go, stop, go, stop. Your child’s stream will become stronger, and the time needed to eliminate fully will decrease. The time needed for this step varies greatly from child to child. I believe that children with lower tone need more time on this step.

At this time you can use pinwheels, horns, or bubbles for your child to blow once they have initiated their stream. Blowing can be useful for older children to increase or maintain their stream. However many young children can not blow successfully using these tools. If blowing toys are a distraction do not use them.

## **Step 8. Keeping the diaper dry.**

Now the goal is to stay dry in-between bathroom breaks. You should have a good idea of how long they are staying dry. You will want to have them go to the bathroom 5 - 10 minutes before you think they need to go. Once our students are good at fully eliminating their bladder, most of them stay dry for about 45 minutes in the beginning.

Times that work well for our students;

- First thing when they arrive at class
- 10 minutes after a snack,
- 10 minutes after lunch,
- Before we go outside to play

I make adjustments to each child's schedule. If they potty halfway through outdoor play, we go in to go potty at that time. Some students need to go potty directly after snack/lunch. For some, it is 20 minutes after snack/lunch.

You will want to make sure to praise your child for staying dry between bathroom breaks. It is important to point this out, so they understand that the goal is to stay dry. It is important never to scold your child for being wet.

When a student is dry, I say, *"You're dry! Good job staying dry!"* I say this with over-the-top excitement. I give a reward for staying dry the first week or two.

When a student is wet, I say, *"You're wet, potties go in the potty chair"* I say this in a very matter-of-fact way, with no disappointment in my voice.

Many students will start to crawl/walk to the bathroom door during this step to let us know they need to go. This is the beginning of communicating that they need to go. Honor attempts to communicate their need to go. Take them to the bathroom even if you don't think they need to go. It is ok if they just want the Ipad. Building communication is very important. They need to know that they will get to go potty if they go to the bathroom.

If the Ipad becomes a problem (you think they are going to the bathroom to get it), then the new rule will be the Ipad after you start to go. I say *"get some potties out. Then I will turn it on."* I allow them to stay on the potty chair with the Ipad for 3 - 5 minutes after they are finished going. Now the Ipad is becoming a reward for going potty instead of a tool to go potty. I only do this if they consistently ask to go to the bathroom and they do not potty.

### **Step 9. Make the move to underwear.**

Many of our students start to wear underwear during the four hours at Little Leaf then change back into a diaper for the rest of the day. This has never confused our kids. I think it is because they are working to keep their diapers dry long before wearing underwear. This method allows parents and children to practice wearing underwear.

My suggestion to parents wondering if their child is ready to switch to underwear is to pick a time and day of the week to focus on potty training. Maybe a Saturday morning for two or three hours. If this is successful, they can add other times to wear underwear. But remember, you are still working to keep the diaper dry as well. Eventually, parents and children understand what is needed to be successful. Parents know when their child will need reminders to go potty. Children will know how to express the need to go by physically going to the bathroom, sign language, or saying potty.

When your child is dry for two hours, it may be time to move to underwear full time. Decide to move to underwear only when you have made sure to have all caregivers on board and know-how to support your child. Make sure you do not have any big lifestyle changes that will make it hard to support your child.

Once you know your child will have the support they need to be successful, make the switch to underwear, and live dryly ever after.

Most of our students follow these steps very closely. Often when students start this process at 18 months to 2-year-old years they are fully potty trained in their 3-year-old year. If they start at the age of 3, they are potty trained in their 4-year-old year. When a student starts at an older age four or older, it often is a little harder to engage them in the process and may take a bit longer for the whole process to be completed. But every child and home is different.

### **Other tips for success.**

- Start to fade the Ipad/tablet once your child is able to fully eliminate in 5 -8 minutes. Many children will need the Ipad/tablet for a bowel movement for longer periods of time.
- Constipation is a cause of incontinence for many children with Down syndrome. Working to keep constipation to a minimum is important for the potty training process.

- Most young children are not great at answering yes/no questions accurately. Keeping this in mind I never ask young students if they need to go. I say “it is time to go potty.” If your child is able to accurately answer yes/no questions, asking may be appropriate. Even if your child can answer yes/no they may still need you to tell them it is time to go potty while they are still in the potty training process.

**\*My child will not sit on the potty. He/she is scared of it.**

If your child is resistant to sitting on the potty chair, they may need to be desensitized to using the potty chair. This is a process to make the child less likely to feel shocked or distressed at situations. Coupling the toileting process with positive responses by substituting a new adaptive reaction to a fearful setting, the child learns a more appropriate response to situations. Encourage your child to touch the potty chair, sit on it with clothes on, praise and reward your child for all attempts. Once your child is no longer resistant you can start to potty train. Watching a sibling sit on the potty can also be useful. This process may be useful in other situations. Most students who need to be desensitized to one thing will need it for another thing. Keep this in mind when your child is resistant to new situations,

**\*My child will only sit for a few seconds.**

Your child may need to work on learning to wait. This is one of the most important skills I feel that we teach students at Little Leaf. Point out any time of the day when your child needs to wait by saying and signing you are waiting. If you are at a red light, in line at a store, tell your child, we are waiting. Teach your child to wait by sitting in one spot while you do something else. Start with very small intervals of time 15 seconds and build to at least one minute. Praise and reward any wait time. Once your child has learned to wait, they will be able to wait on the potty chair.

We want to hear from you! Is this potty training method working for your child? Is the method not working for you? Why is it not working? Do you need additional support? Please contact at [kim@mylittleleaf.org](mailto:kim@mylittleleaf.org), put Underwear 4 k in the subject line, to let us know how you are doing.

Join our Facebook group Underwear 4 Kindergarten

<https://www.facebook.com/groups/526648254990765>

## Chapter 3

### The Urinary Incontinence Connection

According to Niemczyk (2018), a study of 317 participants, found that 46 -73 % of children with Down syndrome have urinary incontinence. According to Kitamura, Kondoh, Noguchi, & et al.(2014) a study with 55 participants found that 18% of children with Down syndrome had a weak stream, prolonged, and intermittent urination, meaning that your child may have difficulty starting or maintaining a stream of urine it also means that your child might have trouble fully eliminating their bladder. (Niemczyk, 2018; Kitamura,Kondoh,Noguchi,et al. 2014)

The reason children with Down syndrome often have urinary incontinence is not yet known, however, there is some research suggesting that incontinence in children with Down syndrome could be caused by constipation rather than hypotonia. Other research suggests that weakness or floppy bladder is the primary cause, while other research points to cognitive delays as the problem. (I do not believe this is the issue)

In conclusion, urinary incontinence, weak stream, prolonged, and intermittent urination is a factor in potty training children with Down syndrome. Allowing longer sit time on the potty chair is important for starting the urine stream. Focusing on going more is important to maintaining and increasing the strength of the stream. Managing constipation in children with Ds to reduce urinary incontinence. Starting this process as young as 18 months of age allows for children with Down syndrome to have a longer time with interventions for compensatory strategy. This will be the most impactful to your child's potty training success.

However, while research is an important factor in creating a best practice approach, it is not reasonable to wait for a conclusion from current research. With my expertise and years of experience with potty training success, I have incorporated the research that is available and used my hands-on reasoning to create a method that has successfully potty trained over 50 students. I am hopeful Underwear 4 Kindergarten can work for your child too!

There are medical interventions including pelvic floor muscle training therapy that may support urinary incontinence. Here is a link for the Seattle children's hospital's pdf on incontinence in children. <https://www.seattlechildrens.org/pdf/PE2627.pdf>

## **About the author**

Kimberly Yaeger  
Head Teacher, Founder,  
and President of  
Little Leaf Learning Center Inc.

Kim Yaeger began her journey with Down syndrome as an educational assistant for a young student with Down syndrome. She wanted to understand his learning profile to guide his success in learning. At this time, she was introduced to Down Syndrome Education International (DSE). She read every research overview they had. The research fascinated and inspired her. After extensively researching Down syndrome education, she developed a strong passion for implementing the research into children's lives. It became clear to her that she was called to execute the studies into a program that children with Down syndrome could access. Little Leaf's early intervention program was the answer to that need. Little Leaf is a developmental and educational center for children with Down syndrome. When old enough, our students go to the public preschool. They still attend Little Leaf in the morning or afternoon a few days a week until Kindergarten. Our small group classes are only a fraction of how our students spend their time.

Kim is a strong advocate for inclusion and believes that an inclusive school environment is best for children with Down syndrome.

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