

# pants4school

**Best practice guidelines  
for professionals on  
toilet training children  
with Down syndrome**



# Best practice guidelines for professionals on toilet training children with Down syndrome.



This guide has been written for all professionals working with children with Down syndrome across any setting. Professionals should appreciate the need to have high expectations, to enable children to achieve their potential. They should understand the importance of early intervention, including for toilet training, and how to go about this for children with Down syndrome.

## Background

In the 1960's toilet training was based on a child-centred approach, with families waiting to start toilet training until their child showed an interest or appeared ready to be toilet trained. That worked very well at the time as the majority of children wore cloth nappies. The mother or main carer would usually sit the child on the potty after feeds, drinks, or meals. Some started this when their child was a few days old, but most did this once their child could sit independently, at about six months of age. This enabled catching some of the wees and poos and saved some washing. The child had the opportunity to learn to recognise that success on the potty resulted in praise.

They also learnt that a full bladder emptied into the nappy resulted in feeling wet and uncomfortable. Families were also able to identify factors such as how often the child passed urine and how long they could stay dry for. These factors often led to the family removing the nappy during the day and starting formal toilet training.

Unfortunately, that 'wait until the child is ready' approach persists today, even though most children wear disposable nappies. This means that many of the factors that would trigger the family to start toilet training are no longer evident. Families delay starting to

work on the skills for toilet training because they do not think the child is ready until the child starts to indicate that they know when their nappy needs changing or is about to be filled. However, the child may not know they are meant to indicate this and may not want to stop wearing a comfortable portable toilet (the disposable nappy), that is so convenient to use.

For children with Down Syndrome there is often an apparent lack of interest in toileting from the child. This then results in a delay in the initiation of work to build the skills needed for toilet training, until the child shows an interest and appears ready.

## Toilet training

Toilet training happens for most children when two main processes interact: physiological maturation of the bladder and bowel, and development of social awareness. For children with Down syndrome, it is often the lack of understanding of social norms that results in delayed toilet training, rather than an inherent problem within the bladder or bowel. However, toilet training is essentially the development of a set of skills. Children with Down syndrome need to be given the opportunity and support to learn those skills. It is important that toilet training for children with additional needs is

proactive and is promoted early. All Health Care Professionals (HCPs) should respond to delayed acquisition of bladder and bowel control in the same way as they would for other developmental delays, such as delayed speech or walking. Referral to a speech and language therapist or physiotherapist would not be put off until it was considered a child was 'ready' to talk or walk. Yet for many children with Down syndrome the introduction of support programmes to facilitate toilet training are either never initiated, or are postponed, in the mistaken belief that the child is not 'ready' and that toilet training will get easier as the child gets older.

Clinical experience has shown that all children benefit from an early introduction to the skills they need for toilet training. They can start to learn to sit on the potty before their first birthday and to learn to manipulate clothes, wash hands etc in the second year of life. Bladder and bowel maturity develop during the early months and there is evidence that starting to work on toilet training after the age of two may cause issues with continence later in childhood. There is also evidence that the process of toilet training may help to promote bladder maturity. Early intervention regarding toilet training can improve the likelihood of successful outcomes for all children with learning disabilities (Rogers 2002).

## The importance of introducing toilet training early

- ▶ Most children with mild to moderate learning difficulties have the same ability to be toilet trained as their typically developing peers (Rogers & Patricolo 2014).
- ▶ There is no consensus or evidence base for how many, or which readiness signs should be present prior to toilet training for any child. In addition, it is likely that some readiness signs will develop during the toilet training process (Kaerts et al 2012).
- ▶ HCPs should remember that up to 30% of all children have a wetting and/or soiling problem at any one time, such as constipation, nocturnal enuresis or daytime wetting. Without appropriate treatment these may persist into adolescence and adulthood (Heron et al 2016). Therefore, assessment of any child with delayed toileting is essential to exclude these as the cause of the delay and to reduce the likelihood of long-term problems.
- ▶ Children with additional needs including Down syndrome are more prone to bladder and bowel conditions than children with typical development (Kitamura et al 2014; von Gontard et al 2016). To fail to offer appropriate and timely assessment is inequitable and inappropriate.



- ▶ Initiation of toilet training after 24 months of age and developmental delay are associated with urinary incontinence later in childhood (Joinson et al 2018; Joinson et al 2009).
- ▶ HCPs, particularly Health Visitors (HV), are in an ideal position to inform families that any wetting and/or soiling problems may not be solely due to a delay in toilet training, or a behaviour problem. They can advise about the importance of assessment to exclude any underlying pathology, provide a correct diagnosis and help inform the design of an appropriate individualized programme, to support development of the skills required for toilet training.
- ▶ HVs can support all parents, including those whose children have Down syndrome, to introduce early potty sitting after weaning, as the first step of a toilet skill development programme. They can also signpost the family to further information and advice.
- ▶ Toilet training is a skill that can be broken into a number of steps. By addressing one step at a time the whole process is made easier and more manageable for the family. 'One step at a time' is an approach that has been used successfully with children with a range of learning difficulties or developmental disabilities; each step brings the child closer to the goal of being toilet trained (Rogers 2010).
- ▶ HCPs should be aware that the automatic provision of 'free' nappies to children with Down syndrome should not be considered until the child has undergone a bladder and bowel assessment and a comprehensive toilet training support programme (Bladder & Bowel UK 2019).





## Common Myths about toilet training children with Down syndrome

**Myth: All children with Down syndrome will have difficulties becoming toilet trained.**

Children with Down syndrome are as individual as typically developing children. Although some may experience difficulties, many will become toilet trained with no problems. They can do so at the same age as their typically developing peers with the right support and approach.

**Myth: If the child cannot talk or walk then toilet training will be impossible.**

This is incorrect. Many children who have delays that affect their speech and/or mobility are successfully toilet trained. The approach may need to be adjusted and the child may continue to need support to access the toilet but can remain clean and dry.

**Myth: It is best to wait until children with Down syndrome are 'ready' to be toilet trained before you make a start.**

There is no evidenced based research that quantifies 'readiness'. Often people misinterpret readiness as the child starting to indicate they want to use the potty or toilet. However, many children, particularly those with learning or processing differences, may not realise that they are meant to let someone know when they want to empty their bladder and/or bowel. This is particularly true if they have always used a disposable nappy and struggle with changing their routines. If people waited until the child indicated that they wanted to use the potty before they introduced any toilet training they would be waiting a very long time.

Constipation is a problem that should always be treated seriously and proactively. Untreated constipation can have a serious effect on an individual's health, wellbeing and continence. It has even caused death in some young adults with learning disabilities.

**Myth: Any wetting or soiling problems in children with Down syndrome are because of their disability and do not require investigating and treating.**

Children with Down syndrome are just as likely (if not more so) to have underlying bladder and bowel problems, including congenital anomalies affecting daytime continence, enuresis and constipation, as their typically developing peers. As a result, every child with wetting and/or soiling problems should be appropriately investigated and treated.

## Toilet training

PADS (Positive about Down Syndrome) promote our four step training programme. This recommends introducing toileting language and regular times for sitting on the potty, from when the child is learning to sit independently, at around nine months. Most children with Down syndrome can be out of nappies and in #Pants4School. Many can toilet train at the same age as their typically developing peers.





## **Dear Future Health Visitor or Dear Future Children's Continence Nurse,**

You've another busy day, full of home visits and I am number three of the children on your list. I understand you are new in post and have not had a child with Down syndrome on your caseload before, so you are not sure what I can achieve or what advice to give my mummy. You're probably nervous as to what to expect of me, how my mummy will be and worried about not saying the wrong thing. Don't worry – you're not the first and won't be the last!! When you arrive at my house you are indeed a little anxious about what you are going to say to my mummy and knock on the door with trepidation, not knowing what to expect.

My mummy opens the door and invites you in. She is happy to see you and is keen to introduce you to me, her beautiful clever boy. She goes off to

make you a cup of tea while you take a seat and have a quick look at me, while I play in the corner of the room. What you see is a child who is not yet talking and not really walking, so immediately your thoughts are that I have learning, and physical disabilities, so am going to struggle to learn new skills. That is what you see.

What you don't see is what my mummy sees - a child who is keen and eager to learn. Who maybe sometimes struggles and takes a little longer to learn new skills but is enthusiastic about life, has tremendous potential and loves to engage with adults. You have already labelled me in your head as having 'special needs' and therefore limited me by making assumptions and decisions as to what I will and won't be able achieve or do.



You have come to carry out a routine assessment and have pages of questions that need to be asked and boxes that need to be ticked, so I know you are keen to get started. You go through the pages and ask the standard questions. As I had not been saying a lot of words you see that I had been referred to the speech and language therapist. However, even though I don't say a lot, I understand everything my family say to me and I love looking at books and pointing to different pictures. I already have great empathy for people, I know if anyone is happy or sad. Mummy asks me to show you my favourite book and you are surprised when I pick it up and bring it to you.

'That's clever' you say, and I give you a big smile and then you smile back. You start to relax.

I was late sitting and am just starting to walk so you check with mummy that I'm seeing the physiotherapist. What you haven't seen is my determination to succeed and how I keep practising my walking by holding on to the furniture. However, you watch as I try to stand up and give you the book – it takes several attempts, but I eventually succeed. 'He's a determined little fellow' you say to mummy with some surprise. 'Oh, he knows what he wants' says mummy 'and works hard to try and get it'.

You tick some more boxes on the form. The assessment is nearly complete, and you get ready to leave.



Then mummy asks you about potty training, and I can see you're quite shocked – because you clearly think that I am 'not ready' and you tell my mummy that. It is not on your checklist list and you had presumed that potty training would be something that would be tackled 'later'. After all, I can see you've assumed that a child who can't talk or walk can't possibly be ready to be toilet trained. What you don't know is that many children with Down syndrome, can be toilet trained at the same age as

their typically developing peers. Toilet training involves a lot of skills, which can be broken into simple steps. It can take me some time to learn new skills, but with lots of practise I can usually manage to achieve them. However, unless people give me the opportunity to learn new skills how can I achieve anything? Lots of children (especially boys!) can struggle with potty training and will need some help, so helping me will be no different than any other child who is not yet reliably clean and dry.



Mummy is keen for me to be toilet trained for when I start school. She tells you that I already sit on the potty after meals and now mostly do all my poos there (and the occasional wee!) and have very few 'dirty' nappies. I can see you're surprised - Gosh, you think - this regular potty sitting is something you don't even suggest to parents of 'typically developing' children. This makes you think that gradually introducing regular potty sitting is perhaps something you should be advising all parents to do.

Mummy points out to you that I have been referred on to other professionals for help with walking and talking, so wonders if there is anyone who can help with toilet training. This gets you thinking that perhaps you can give mummy the same advice that you give to other mummies about potty training. Something that you didn't even think about before now. You tell mummy that you will also speak with the children's continence nurse, who can provide some extra advice and information, as necessary.

At the end of the visit you come to realise that I am not really unlike any child on your caseload. After all, all children are individuals with differing needs and abilities. As you leave through the front door and say goodbye, you now don't see a 'special needs' child, you now see me!

Love

The little boy with so much potential given the opportunity!

*Written by June Rogers MBE*

**Retired Children's Specialist Continence  
Nurse (35 years toilet training children  
with Down syndrome)**

## Links to further information about Down syndrome

Please join our closed Facebook page for more information and ensure you have high expectations around this life skill:

For parents of and professionals working with a child up to 5 years of age

For parents of and professionals working with a child/young person over 5 years of age

If you would like any further information about Down syndrome, please contact PADS. We are developing an online programme of virtual training events that nurseries and other preschool settings can access. There are also support groups across the UK who run a varied programme of training events through the year for professionals to understand more about working with children and young people with Down syndrome.

There is a closed Facebook group exclusively for professionals working with children with Down syndrome in preschool settings. Please join to share resources, best practice and experiences and to ask for advice.

[www.facebook.com/groups/1969218099768760](https://www.facebook.com/groups/1969218099768760)

For professionals working with pupils in primary school please join this group

## Links to further information about Down syndrome:

[positiveaboutdownsyndrome.co.uk](https://positiveaboutdownsyndrome.co.uk)

[downsed.org](https://downsed.org)

[downs-syndrome.org.uk/about/](https://downs-syndrome.org.uk/about/)

## Step-by-step toilet development programme

Becoming toilet trained involves the development of a certain set of skills. Our step-by-step toilet skill development programme enables children to learn about and develop those necessary skills - giving them the opportunity to become toilet trained and wear #pants4school.

Pants4School Training Programme

## Recommended videos to watch (Youtube)

Tom's Toilet Triumph

Further information can be accessed from [www.downsyndromeuk.co.uk](https://www.downsyndromeuk.co.uk)



## References

**Bladder & Bowel UK (2019)** Guidance for the provision of continence containment products to children and young people A consensus document available from <https://www.bbuk.org.uk/wp-content/uploads/2019/03/Guidance-for-the-provision-of-continence-containment-products-to-children-2019.pdf>

**Heron J et al (2016)** *Trajectories of urinary incontinence in childhood and bladder and bowel symptoms in adolescence: prospective cohort study* BMJ Open 7 e014238

**Joinson C et al (2018)** *A prospective cohort study of biopsychosocial factors associated with childhood urinary incontinence* European Child & Adolescent Psychiatry <https://doi.org/10.1007/s00787-018-1193-1>

**Joinson C et al (2009)** *A prospective study of age at initiation of toilet training and subsequent daytime bladder control in school-age children* Journal of Developmental and Behavioral Pediatrics 30, 5 385-393

**Kaerts N et al (2012)** *Readiness signs used to define the proper moment to start toilet training: a review of the literature* Neurology and Urodynamics 31: 437-440

**Kitamura A et al (2014)** *Assessment of lower urinary tract function in children with Down syndrome* Pediatrics International 56, 6 902-908

**Rogers J (2002)** *Solving the enigma: toilet training children with learning disabilities*. British Journal of Nursing 7;11(14):958, 960, 962

**Rogers J (2010)** *One step at a time, how to toilet train children with learning difficulties*. Nursing Times 106(47):19-20.

**Rogers J, Patricolo M (2014)** *Addressing continence in children with disabilities*. Nursing Times 110: 43, 22-24

**Von Gontard A et al (2016)** *Do we manage incontinence in children and adults with special needs adequately?* ICI-RS 2014 Neurourology and Urodynamics 35 304-306