DSUK Down Syndrome UK

Bladder & Bowel UK

Best practice guidelines for professionals, supporting skill development for toilet training in all children, including those with learning disabilities and developmental differences:

A consensus document

Date of initial publication: November 2023
Version 2: June 2024
Date of next review: November 2026
13137

DOCUMENT PURPOSE	National guidance
DOCUMENT NAME	Best practice guidance for professionals - Supporting skill development for toilet training in all children, including those with learning disabilities and developmental differences: A consensus document
PUBLICATION DATE	November 2023 Version 2 April 2024
MAIN AUTHORS	June Rogers MBE, Independent practitioner, Specialist Children's Nurse (retired), Consultant at Down Syndrome UK Davina Richardson, Specialist Children's Nurse, Bladder & Bowel UK
TARGET AUDIENCE	Integrated Care Boards, Children's Leads, Health Board Clinical Leads, Health and Social Care Board Clinical Leads, Primary Care Network Clinical Leads, NHS Foundation Trust CE's, Directors of Nursing, Local Authority CE's, NHS Trust Boards, Allied Health Professional Service Leads, GPs, Paediatricians, Directors of Nursing, Directors of Children's Services, NHS Trust CE's, Children's Bladder and Bowel Service Leads, Educational Establishments, Training Establishments, Social Care Providers, Early Learning Years Providers, Learning Disability Service Providers, all who work with children and young people, members of the public including parents, carers, children and young people
ADDITIONAL CIRCULATION LIST	Learning Disability Networks, Adult Bladder and Bowel services
DESCRIPTION	Consensus guidance document regarding the introduction of early toilet skill development programmes for all children, including those with learning disabilities and developmental differences, to ensure all children have access to appropriate advice and support to enable age-appropriate attainment of potential for acquisition of continence, and early identification and appropriate interventions for any bladder or bowel health issues
SCOPE AND PURPOSE	This document is aimed at anyone working with or supporting a child of any age to enable them to develop the skills required for toilet training.
CROSS REFERENCE	Guidance for the Provision of Continence Containment Products for Children and Young People: A Consensus Document (Bladder & Bowel UK 2021), Children's Continence Commissioning Guide (PCF 2023) Excellence in Continence Care (NHS England 2018) Healthy Child Programme 0 to 19: Health Visitor and School Nurse Commissioning (Public Health England 2021)
CONTACT DETAILS FOR FURTHER INFORMATION	Davina Richardson, Children's Specialist Nurse Bladder & Bowel UK davina.richardson@disabledliving.co.uk June Rogers MBE Independent Practitioner info@downsyndromeuk.co.uk
REVIEW DATE	November 2026

DSUK Down Syndrome UK Bladder & Bowel UK

DISCLAIMER

It is expected that health, education, social care, early learning years staff and any other professional involved in the care of children and young people, including those with learning disability or developmental differences will use their professional knowledge, expertise and judgement, in applying the general principles and recommendations contained in this document. Recommendations may not be appropriate in all circumstances. The decision to adopt specific recommendations should be made by the practitioner, considering the individual circumstances of each child or young person, their environment and the available resources.

Options should be discussed with the family, the child (according to their development and understanding) and other professionals involved in the child or young person's care and/or education on a case-by-case basis, as appropriate. Continued use of disposable products may not only delay acquisition of skills for toilet training but may mask medical issues that should be assessed and treated.

It is essential that the health, education and social care professionals advising individual families about toilet training, have an awareness of expected bladder and bowel development and function and recognise when more detailed assessment of bladder and bowel health is required. Healthcare professionals who undertake bladder and/or bowel assessments must be competent to do so. This will help ensure that no child's ability or potential to achieve the skills required for toilet training are underestimated. It will also ensure that children who do not achieve toilet training in an age-appropriate way, or where delay is anticipated due to disability or developmental difference, will receive appropriate and timely interventions and support.

The information and recommendations in this document are based on evidence, where currently available and on consensus of best practice. The authors have made efforts to ensure that all links and references in this document are relevant and appropriate. However, they do not accept any liability for maintenance of links, or to the completeness, accuracy, reliability, suitability, availability or content of the links or references. Any reliance or use of them remains the responsibility of the individual practitioner.

All references to children or child in this document refer to any child or young person, who requires support to develop the skills for toilet training.

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

This document will use the term learning disability to refer to all children with learning disability, developmental delay, or developmental differences.

FOREWORD: ALISON MORTON CEO, INSTITUTE OF HEALTH VISITING

Gaining mastery of your own bladder and bowel function is an important milestone in a child's development. However, toileting practices and advice have changed over the years, leaving many parents confused about the right approach to take for their own child. And this can be even more confusing for parents of children with disabilities or diagnosed conditions such as autism or Down Syndrome. Messaging for parents and practitioners is also heavily impacted by commercial influences and industry marketing tactics to delay toileting and prolong the use of nappies and disposable nappy pants under the guise of 'waiting until children are ready'. This has a human, financial and environmental cost.

As a parent of a child with cerebral palsy myself, I have experienced first-hand the impact of low societal expectations of children with disabilities. I was given unsolicited advice that my child would probably be incontinent forever and I needed to accept a life of nappies for him. Fortunately, I was also lucky to work with experts who took a much more personalised approach, working with me to find the best solution for my child. And this is the overarching message of these helpful 'Best Practice Guidance for Professionals'. I fully support the aims of this much-needed resource to facilitate a consistent, individualised approach to toileting for every child.

This resource not only offers a valuable overview of the latest evidence, research and clinical experience of leading national experts in the field of toileting and managing bladder and bowel issues, but also provides practical guidance on supporting all children, including those with disabilities and diagnosed conditions, with toilet training. The authors encourage all professionals to maintain high expectations for the ability of all children, including those with learning disabilities, to acquire the skills for toileting.

Implementing the guidance will significantly improve the knowledge, expectations, skills and competence of those working in this field and the support offered to families. We know that getting the right help at the right time can make a big difference. This is so important to ensure that all children reach their full potential in this aspect of personal care and achieve maximum possible independence. In contrast, the authors make the strong case that unnecessary delays and low expectations are limiting children's life chances and can have lifelong consequences. Getting this right is not really a choice, it is fundamental for children's dignity, safety and quality of life. As such, this document is a very positive development and one of the most important and timely publications on this topic in recent years.

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

that all children reach their full potential in this aspect of personal care and achieve maximum possible independence. In contrast, the authors make the strong case that unnecessary delays and low expectations are limiting children's life chances and can have lifelong consequences. Getting this right is not really a choice, it is fundamental for children's dignity, safety and quality of life. As such, this document is a very positive development and one of the most important and timely publications on this topic in recent years.

EXECUTIVE SUMMARY

This guidance is based on evidence and research where available, and on clinical experience. Much of this evidence and experience comes from work with children with both typical development and with those whose additional needs are due to diagnosed conditions, such as Down syndrome and autism. This includes a project with Down Syndrome UK that has been ongoing for over three years and has supported more than a thousand families to toilet train their children with Down syndrome.

For children with diagnosed disabilities, difficulties in toilet training may be anticipated. However, any child may struggle with some aspects of learning, including with the attainment of bladder and bowel control. Therefore, the recommendations in this guidance should be helpful for all.

A study by Eke et al (2021) highlighted the lack of evidence-based interventions regarding toilet training children with a neurodisability. They recommended better training for health, education and care professionals about toileting, informed by evidence and the lived experiences of children and their families. They concluded that it is vital that children and young people with a neurodisability have early access to regular, integrated assessment of their bladder and bowel health, and are fully supported with appropriate personalised treatment.

As there is currently no research-based validated guidance regarding toilet training for children, including for those with learning disabilities, this is a consensus based, peer reviewed best practice document. This guidance is intended to support achievement of potential for toilet training for all children, including those with identified conditions, those with no formal diagnosis and those with typical development who are having difficulties.

Professionals should appreciate the need to have high expectations, to enable children to achieve their potential. They should understand the importance of early intervention, to promote development of the skills that are required for maximum possible independence with toileting and know how to approach this.

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

KEY RECOMMENDATIONS

- The families of all children who are identified as having any form of learning disability, or who are suspected of having any disability or condition that may have an impact on toilet training, must be offered support in the first year of life, or as soon as the disability or condition is recognised, from a healthcare professional with particular interest and expertise in toilet training.

- All professionals must maintain high expectations for the ability of all children, including those with learning disabilities, to acquire the skills for toileting. This will ensure that they reach their potential in this aspect of personal care, that is fundamental for independence and quality of life.

- All children with a condition or disability that may delay achievement of the skills for toilet training must be offered an early assessment of their bladder and bowel health with the identified treatment required provided by a healthcare professional who has the interest and expertise for this.

- Containment products must not be offered to children with learning or other disabilities, developmental differences, or conditions that may delay acquisition of the skills required for toilet training, without them having had at least six months supported toilet skill development programmes, following a comprehensive assessment and with all identified interventions undertaken in line with the Guidance for Provision of Continence Containment Products to Children and Young People: A Consensus Document 2021. Products would then only be offered from age 5 in line with the guidance.

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

INTRODUCTION AND PURPOSE

This guidance has been written for all professionals working across any setting with children or young people who are struggling with developing the skills required for toilet training, with attainment of continence, or where it is anticipated that these issues may arise. Many will have a diagnosed or suspected learning difficulty, learning disability, developmental delay, or neurodevelopmental difference, which may be associated with learning difficulties. However, the document is also relevant to children with apparently typical development who are struggling to acquire the skills required for toilet training, for any reason.

The purpose of this guidance is:

- to ensure that all children, including those with learning disabilities, developmental differences or other conditions that may impact on toilet training, are given the opportunity and support to achieve their potential for developing the skills required for toilet training from the early months of life or as soon as any issues are identified.

- to facilitate a consistent, individualised approach to ensure that every child has the opportunity and support to acquire the skills needed to achieve their full potential and maximum possible independence with toileting and maintenance of personal hygiene.

- to ensure that bladder and bowel health is promoted and optimised and ensure comorbidities are recognised and addressed for all children and young people.

- to suggest a pathway for supporting toileting skill development that can be used wherever the child spends their time, including home, educational facilities and social care settings[1].

BACKGROUND

Prior to the advent and widespread use of disposable nappies children were usually put on the potty after feeds, drinks, or meals. Some families started this by holding their child over a potty from as early as a few days old, with most introducing this when their child could sit independently, at about six months of age.

Traditional practices that made use of the child's natural reflexes and elimination patterns resulted in reduced washing, the child learned to sit in the appropriate place, that emptying their bladder and/or bowel on the potty resulted in praise, that a wet or soiled washable nappy was uncomfortable and that indicating a full nappy resulted in it being changed. Additionally, families were able to identify when their child was likely to need the potty, reducing elimination into a nappy, which led to its early removal during the day. The family took their child to the potty when they predicted it was likely be needed. This continued until their child learnt to respond to bladder and bowel signals by either asking for the potty or toilet, or by accessing it independently.

[1] A toilet skill development programme is outlined in Appendix One on page 18.

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

Currently families are often advised to wait until their child is exhibiting certain readiness signs, although these are not clearly defined and there is no evidence base for them (Kearts et al 2012). This approach is not appropriate or helpful. Children are no longer developing the skills for toilet training in the way they did when wearing washables. They are not being introduced to sitting on a potty and, as they are comfortable in the disposable, they may not know they are meant to indicate when they have opened their bowels or passed urine.

Many parents are uncertain about how to address toilet training. Starting nursery school, the age of the child or other extrinsic factors are often the main triggers for commencing potty training, with only 27.8% starting due to the child requesting it (Aggelpoel et al 2018).

Children with learning disabilities and developmental differences may not develop the social awareness that they should be clean and dry and their families may be even more uncertain of how to address toilet training than the families of their typically developing peers. Furthermore, delays in acquisition of motor, cognitive, communication and other skills and sensory differences may result in the assumption that delays in toilet training are inevitable. Hence, too frequently, the work to build the skills needed for toileting, is not initiated in an age-appropriate way. Additionally, developmental differences may result in decreased awareness of bladder and bowel signals, and the behaviour and habit of using the nappy becomes increasingly entrenched.

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

TOILET TRAINING

The age of toilet training has increased in recent decades (Nilsson et al 2022, Vermandel et al 2008), although it varies, between cultures and families (Horn et al 2006). There is evidence that toilet training is started later and takes longer for children with Down syndrome than for children with typical development. They are also more likely to be incontinent after toilet training (de Carvalho Mrad et al 2018, Powers et al 2015). Despite a lack of research evidence for other conditions, experience suggests later and more protracted toilet training is the case for many children with developmental differences, but most should be able to toilet train at a similar age to their typically developing peers, if provided with appropriate support.

Dreher et al (2022) identified that toilet training later than is typical for children with learning disability due to Down syndrome is associated with social stigma and negative outcomes for social development, resulting in reduced social opportunities and low expectations when starting school. This is likely to be true for any child who has not attained continence at the same age as their peers. Furthermore, there is evidence that delayed toilet training increases prevalence of issues with bladder health later in childhood for all children (Joinson et al 2008, Joinson et al 2018, Wang et al 2019, Li et al 2020). For children with learning disabilities, it is often the lack of understanding of social norms and what may be achievable that result in families being advised to delay toilet training, rather than an inherent problem within the bladder or bowel. However, the impact is still likely to be felt[2].

Currently there is minimal research to inform best practice on how and when to introduce toilet training for children with learning disabilities (Eke et al 2021) and for all children the literature is 'complex, unclear and divided' (Kaerts 2012). However, toilet training is essentially the development of a set of skills. All children should be proactively supported to learn those skills early in childhood.

Professionals involved in a child's care and education should respond promptly to any issues or anticipated difficulties with acquisition of bladder and bowel control, in the same way as they would for other developmental issues, such as delayed speech or walking. They should recognise that most of the signs traditionally considered as demonstrating readiness for toilet training can and should be taught.

Learning the skills required for toilet training does not usually get easier as the child gets older. This is because the behaviour of using the nappy is increasingly embedded with time. Furthermore, with disposable nappy use, bladder and bowel health issues may be missed.

[2] Many of the myths surrounding toilet training children with disabilities are discussed in Appendix Two on page 23.

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

EARLY INTRODUCTION OF TOILET TRAINING

Children can start to learn to sit on the potty, with physical support if required, before their first birthday and then go onto learn to manipulate clothes, wipe, flush, wash hands etc as part of a toilet skill development programme. A step-by-step programme has been successful in enabling children with Down syndrome to be toilet trained before starting school (Rogers & Enoch 2020). Therefore, similar programmes may be helpful to all children, particularly those who have a potential delay in acquisition of bladder and/or bowel control due to disability or developmental difference.

The initial aim of a toilet skill development programme is to enable the child to remain reliably clean and dry, before going on to develop the additional skills that will enable them to achieve maximum independence with all aspects of the toileting process. Some children with learning or physical disabilities may continue to need some adult support with elements of the toileting process on a regular or occasional basis. However, being able to use the toilet or potty appropriately, even with support, is likely to improve quality of life for the child and their family[3].

INTRODUCING A TOILET SKILL DEVELOPMENT PROGRAMME

'One step at a time' was developed in 2009 in Australia as a toilet training programme for children with learning disabilities. The programme breaks the process of developing the required skills for toileting into steps, with each step bringing the child closer to the goal of becoming as independent as they can be. This programme, aimed at children from around the age of 2 years, proved successful (Rogers 2010).

More recently early potty sitting was introduced to children with Down syndrome as part of proactive work to help prevent and manage constipation following weaning as part of the #pants4school initiative. Parents were encouraged to sit their child on a potty from the age of about 6 – 9 months to promote complete rectal emptying. It soon became apparent that, not only were the infants able to open their bowels more easily, but families reported that their child appeared to wait until they were sitting on the potty to do so (Rogers and Enoch 2020).

Consequently, early potty sitting was introduced more widely as the first skill the children required. The programme was further developed and has now been successfully used to support more than a thousand children with Down syndrome to begin their toilet training journey in infancy and achieve continence. This structured approach is supported by Dreher et al (2022), who identified that the most successful method of toilet training children and adolescents with Down syndrome was a toileting schedule with reinforcement and the family prompting their child to use the toilet.

[3] The programme is outlined in Appendix One on page 18.

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

Bater et al (2020) demonstrated that routines and consistent expectations reduced behavioural challenges such as defiance and toilet refusal. Additionally, the toileting schedule often resulted in 'accidental' voiding into the toilet, aiding the child's understanding of what they are being asked to do. These findings are consistent with the neurodevelopmental profile of individuals with Down syndrome (Dreher et al 2022) and other learning disabilities. However, they also mirror the traditional approach used by most parents who practice infant-led pottying, where the baby or young child is held over, or placed on an appropriate receptacle at the time they are most likely to need to void or open their bowels. Anecdotal evidence suggests that children exposed to these routines become continent at a much younger age than those who use disposable nappies.

ENSURING COMPLIANCE AND MOTIVATION

Individuals with learning disabilities often display lack of motivation to complete a task (Fidler and Nadel 2007) and may not be intrinsically motivated to use the toilet for several reasons: it is easier to use a nappy or wet or soil in pants than it is to discontinue the current activity, get to the toilet or potty, manipulate clothing, void or defecate, clean and go back to the activity. In addition, toileting requires fine and gross motor coordination skills that are known to be affected in many with learning disabilities (Winders et al 2019, MacDonald and McIntyre 2019). They may also struggle with working memory. Therefore, using the toilet is more of an effort for a child with learning disability than for a child with typical development.

Positive reinforcement in the form of praise or tangible rewards may be necessary to motivate many children, to make the effort to go to the toilet. Equally, adult-led prompting and support in the bathroom is needed at the beginning of the programme, both as motivation and to making toileting less onerous, which encourages compliance. As the child makes progress strategies are instigated to promote achievement of maximum independence.

Motivators or rewards must be meaningful for the child and easily accessible for the family. They should be given immediately the child has performed the desired behaviour and, importantly, whatever motivator is given should not be available at any other time, otherwise it will lose its attraction to the child. Changes to the motivator or reward may be needed to keep the child engaged.

MANAGING INCONTINENCE AFTER NAPPY REMOVAL

Once the nappy has been removed some children, who previously stayed dry for 90 minutes or more, may start to pass small volumes of urine into their pants frequently. These wetting incidents often result in families reverting to nappies either of their own accord, or due to professional advice, as the children are considered to have insufficient bladder control to be toilet trained at that point.

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

However, experience suggests that these frequent wetting incidents are more likely the natural response of the child to becoming aware of the new sensation of feeling wet, which they have not previously experienced. They understandably respond by stopping themselves from further voiding prior to their bladder being fully emptied. Their bladder then rapidly refills, resulting in another void, which the child will again stop as soon as they start to feel wet. Rather than indicating a lack of readiness, frequent small voids are often part of the learning process and may mark the beginning of the development of bladder control.

Parents should be advised and supported to work through the frequent wetting, as most children will gradually improve over a few days, until they are eventually able to stay dry in between potty/toilet visits.

REINFORCING DEVELOPING TOILETING SKILLS

As with learning any new skills, the processes may need to be reinforced until they are fully embedded. Regression of toileting skills is not uncommon, particularly if there are any changes in the child's life such as starting school or having a new sibling. Deher et al (2022) found that 24.8% of families reported that their child experienced a loss in their toileting skills at some point during the training process. Families should be advised this may happen and of the need to regularly reinforce the skills, which can be done through maintenance of routines, toileting social stories, songs, or videos, or using visual toileting sequencing cards.

For children over the age of five years, who struggle to understand the concept of going to the toilet or who appear to not recognise when their bladder is emptying, the use of a wetting alarm is often helpful (Lancioni et al 2002, Larson 2016). Clinical experience has demonstrated the success of body-worn wetting alarms to help children associate being wet with bladder signals and to respond appropriately by going straight to the toilet[4].

KEY POINTS: THE IMPORTANCE OF INTRODUCING THE SKILLS FOR TOILET TRAINING EARLY

- Health visitors, early learning practitioners and educators can support all families, including those whose children have learning disabilities, to introduce potty sitting at the same time as weaning and to commence further toilet skill development programmes from the child's second year. They can also signpost the family to further information and advice.

- Early intervention to learn the skills for toilet training can improve the likelihood of successful outcomes including for children with learning disabilities (Rogers and Enoch 2020).

- Most children with learning disabilities have the same ability to be toilet trained as their typically developing peers (Rogers & Patricolo 2014) and with the right support may achieve this at a similar age.

[4] There is information about using a wetting alarm to support toilet training on the Bladder & Bowel UK website at Using a wetting alarm to support a toilet training programme.

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

- Introduction of the skills for toilet training after 24 months of age is associated with increased risk of urinary incontinence later in childhood (Joinson et al 2018, Wang 2019, Joinson et al 2009).

- 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).

- Toilet training is a skill that can be broken into a number of steps. By addressing the steps sequentially, the whole process is made easier and more manageable for the family (Rogers & Enoch, 2020).

- 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 by a healthcare professional, is essential to exclude these as the cause of the delay and to reduce the likelihood of long-term problems.

- Children with learning disabilities 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.

- Healthcare professionals, particularly health visitors, 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 individualised programme, to support development of the skills required for toilet training.

- Professionals working with children who have learning disabilities and their families should be aware that the automatic provision of disposable products to contain incontinence should not be considered until the child has undergone a bladder and bowel assessment and a comprehensive supported toilet training programme in line with the Guidance for the Provision of Continence Containment Products to Children and Young People (Bladder & Bowel UK 2021).

GUIDANCE DEVELOPERS

June Rogers MBE Independent Practitioner, Children's Nurse Specialist (retired), Consultant to Down Syndrome UK

Davina Richardson Children's Nurse Specialist, Bladder & Bowel UK, Manchester

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

EXTERNAL REVIEWERS

The guidance developers are grateful to all those who reviewed the document. These include those listed below and others, including professionals working at different grades in an integrated community bladder and bowel service in the south of England, children's bladder and bowel nurse specialists, teachers, parents, and health visitors.

Lou Aston, Lecturer, BSC QTS (Hons) MA Early Years, Leeds Beckett University
Kim Baker Paediatric Continence CNS Team Leader Cardiff and Vale University Health Board

Rebecca Daniels, Community Children's Nursing project lead / chair UK Community Children's Nursing Network, Queens's Nursing Institute

Elaine Davies, School and Public Health Nurses Association representative
Nicola Enoch, parent and CEO Down Syndrome UK

Jean McCracken, Children's Continence Lead Nurse, Southern Health & Social Care Trust, Northern Ireland

Michelle Newton, Children's Bladder and Bowel Specialist Nurse, Gateshead Health NHS Foundation Trust

Aoife Price, Health Visitor, Gloucestershire Health and Care NHS Foundation Trust

Samantha Tapscott-Roberts, Specialist Nurse Paediatric Bladder & Bowel Service, Central Cheshire Integrated Care Partnership Mid Cheshire NHS Foundation Trust

Jo Tindle, parent

No conflicts of interest were declared by either of the authors or any of the reviewers.

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

REFERENCES

Aggelpoel TV et al (2018) Parents' views on toilet training: a cross-sectional study in Flanders Nursing Children and Young People 30, 3, 30 – 35

Bater LR, Jordan SS (2017) Child routines and self-regulation serially mediate parenting practices and externalizing problems in preschool children and adolescents. Child Youth Care Forum. 46, 243–259

Bladder & Bowel UK (2021) 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/2022/08/Guidance-for-the-provision-of-continence-containment-products-to-children-paediatric-Bladder-Bowel-UK.pdf Accessed 4.4.2024

de Carvalho Mrad FC et al (2018) Prolonged toilet training in children with Down syndrome: a case-control study J. Pediatr. (Rio J.) 94, 3 May-Jun 2018 Doi: 10.1016/j.jped.2017.06.011

Dreher T et al (2022) Toilet Training in Children and Adolescents with Down Syndrome. J Dev Behav Pediatr. 1, 43, (6) e381 – e389

Eke H et al. (2021) Improving continence in children and young people with neurodisability: a systematic review and survey. Health Technol Assess; 25 (73)

Fidler DJ, Nadel L. (2007) Education and children and adolescents with Down syndrome: neuroscience, development, and intervention. Ment Retard Develop Disabilities. 13: 262 – 271

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

Horn I et al (2006) Beliefs about the appropriate age for initiating toilet training: Are there racial and socioeconomic differences? The Journal of Pediatrics 149 (2): 165 – 8 DOI: 0.1016/j.jpeds.2006.03.004

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

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

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

REFERENCES CONT.

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

Lancioni GE et al (2002) Urine alarms and prompts for fostering daytime urinary continence in a student with multiple disabilities: a replication study. Percept Mot Skills; 94 (3 Pt 1): 867 – 870

Larsen KL, Jordan SS. (2020) Organized chaos: daily routines link household chaos and child behavior problems. J Child Fam Stud. 29: 1094 – 1107

Levato LE, et al (2016) Use of urine alarms in toilet training children with intellectual and developmental disabilities: A review. Res Dev Disabill; 53-54: 232 – 241

Li X et al (2020) Disposable diaper overuse is associated with primary enuresis in children Nat Res Scientific Reports 10: 14407 doi.org/10.1038/s41598-020-70195-8

MacDonald M and McIntyre LL (2019) The relationship of age, early motor skills and observable child behaviors in young children with developmental delays Res Dev Disabil. 2019 October; 93: 103445. doi:10.1016/j.ridd.2019.103445.

Nilsson T et al (2022) Bowel and bladder function in infant toilet training (BABITT) – protocol for a randomized two-armed intervention study BMC Pediatrics Doi: 10.1186/s12887-022-03355-6

Powers MK, et al. (2015) Trends in toilet training and voiding habits among children and adolescents with Down syndrome. J Urol. 194 :783 – 787

Public Health England (2021) Healthy child programme 0 to 19: health visitor and school nurse commissioning available from https://www.gov.uk/government/publications/healthy-child-programme-0-to-19-health-visitor-and-school-nurse-commissioning Accessed 4.4.2024

Rogers J (2010) One step at a time: how to toilet train children with learning disabilities. Nursing Times; 106: 47

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

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

REFERENCES CONT.

Rogers J, Enoch N (2020) Early intervention toilet training for children with Down syndrome Br J Nurs 29 (22): 1325 – 1326 doi: 10.12968/bjon.2020.29.22.1325

Vermandel A et al (2008) How to toilet train healthy children? A review of the literature Neurourology and Urodynamics 27:162–166 (2008) Doi: 10.1002/nau.20490

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

Wang X Z et al (2019) The influence of delay elimination communication on the prevalence of primary nocturnal enuresis—a survey from Mainland China. Neurourology and Urodynamics 38, 5, 1423 – 1429

Winders P et al (2019). A schedule of gross motor development for children and adolescents with Down syndrome. J Intellect Disabil Res. 63: 346 – 356

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

DSUK Down Syndrome UK Bladder & Bowel UK

APPENDIX ONE

PANTS4SCHOOL TOILET SKILL DEVELOPMENT PROGRAMME OVERVIEW

Introduction

Down Syndrome UK (DSUK) and Positive About Down Syndrome (PADS) developed a #Pants4School project, with the aim to enable children with Down Syndrome to develop the skills, awareness and understanding needed to be toilet trained. This project has enabled over a thousand children with Down syndrome to toilet train and many of them have started school in pants, rather than disposable products.

This programme can be used or adapted for use by any child, at any age, with any developmental ability or physical or learning disability.

It is recommended that, if possible, the programme should start when the child starts weaning (at 6 – 9 months old). However, for children who are older than this, the programme should start as soon as possible. For children who are over the age of 2 years old, steps 1 and 2 (see below) could be combined. It may also be appropriate to introduce elements of step 3 such as learning about pulling pants up and down, flushing the toilet and washing hands at the start of the programme.

Regardless of how old the child is, communication is the key. The families should be encouraged to talk about, sign, and show an appropriate picture, or for visually impaired children, families should give them an object of reference or sing a potty song, every time they change a nappy or sit their child on the potty or toilet. This can help their child understand the concept and sows the seeds for them learning to go to the toilet on their own (self-initiate) later.

It is important that everyone looking after the child is aware of the programme and follows the same process that the family is working on at home.

Step One - Getting started

- Healthy eating and drinking habits should be established as far as possible, as this helps prevent constipation and establishes bladder health.

- The child should be changed in the bathroom area, if possible. This helps the child make the connection between their bladder and bowel function and the toilet.

- Let the child see faeces from the nappy/potty being tipped down the toilet and the toilet being flushed.

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

- The families should be given advice, if necessary, about appropriate equipment for their child. They are likely to need a potty, or a toilet seat reducer and a step. Some children, particularly those with motor issues and/or sensory needs may benefit from an occupational therapy assessment for the provision of the correct equipment and to address any sensory issues with the environment[5].

- The child should be introduced to sitting on the potty (or toilet depending on their age, physical size, family preference and individual needs) for a short time once or twice a day. The time should be determined by how long the child will sit before trying to get off. The family should aim to let them get off the potty or toilet before the child attempts to do so on their own, even if this means they only sit for a few seconds to start with. This can be done with support for children who are unable to sit independently.

- Games can be used to increase the child's awareness of what is expected and to remind them of the sequencing for toileting[6].

- Once the child is happy to sit on the potty or toilet for at least a few seconds once or twice a day, the family may move onto step two.

Step Two – Introducing regular potty or toilet times

- When the child is sitting for at least a few seconds, the length of time they are encouraged to sit on the potty or toilet should be gradually increased, until they can sit happily for two to five minutes. The use of distraction, with bubbles, songs, books, squeezy or tactile toys etc. are often helpful to encourage the child to remain on the potty for the required amount of time.

- The frequency of sitting on the potty or toilet is then gradually increased, until they are eventually sitting for two to five minutes when they wake up, after all meals and drinks, before a bath and before bed.

- For children starting the skill development programme at a few months old, sitting on the potty/toilet will soon become part of everyday routine. Older children may need a reward or motivator for sitting on the potty or toilet to encourage compliance.

- The family should be advised to consider letting their child see other family members using the toilet.

- Families should be encouraged to talk to their child about wee and poo when they are going to use the toilet themselves and when changing their child's nappy. They should also talk about the need to stop what they are doing and go to the toilet or potty when they need to do a wee or poo.

[5] There is information on how sensory needs impact on toilet training in the Bladder & Bowel UK leaflet The impact of sensory issues on toilet training
[6] Twinkl has free games available that were developed by Down Syndrome UK, but may be appropriate for any child or young person at https://www.twinkl.co.uk/resources/twinkl-partnerships/down-syndrome-uk

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

- Families should be encouraged to talk to their child, sign to them and show them a picture of the potty, or use their object of reference or song, whenever taking them to the potty or toilet. They should encourage their child to copy the communication (e.g. repeat the word, sign, or song, or return the picture or object of reference) with lots of praise for successfully doing so. This is the first step in the child eventually learning to self-initiate.

- Sitting on the toilet, as well as the potty, should be introduced early if possible. The child will need a toilet seat reducer that does not move when placed on the toilet and a step that is of sufficient height. The equipment should enable the child to sit with their bottom well supported, with their feet flat on a firm surface and with their knees higher than their hips, as this position promotes bladder and bowel emptying.

- Families should give their child lots of praise if they pass urine or open their bowels on the potty or toilet. This may be sufficient to encourage younger children. Older children may need an instant reward. Families should be advised to give specific praise such as 'Good boy for sitting on the toilet', 'Good girl you did a wee/poo.'

- Role play with dolls and teddies going for a wee and poo and having clean dry pants may be helpful.

- At the end of this step, children should be able to sit happily on the potty or toilet for at least a minute for each year of their age (long enough to do a wee or a poo) with some occasional success.

Step Three – Timed Toileting

- For timed toileting it is important for families to identify their child's usual bladder and bowel habits.

- To find out how often their child passes urine and opens their bowels a baseline assessment is carried[7]. This involves the family:

  I. Putting a folded kitchen towel in their child's nappy

  II. Checking their child's nappy every hour that they are awake and make a note if it is wet, dry or soiled. The kitchen towel should be replaced if it is wet and the nappy should be changed when it is full or soiled

  III. Continuing with this for at least three days, although these do not have to be consecutive days

  IV. Making a note on an assessment chart when their child is wet, or soiled, when they have eaten or had something to drink.

[7] A baseline assessment chart is available in Appendix Three on page 24.

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

- The assessment charts will allow the family to identify roughly how long their child goes between voids and any pattern for this and for bowel actions. They must then take their child to the potty or toilet at the time interval they can stay dry for, as identified by the assessment. However, they should not take their child more often than once every hour.

- The family must keep a record of whether their child is wet or dry when taken to the toilet or potty and whether they use the toilet or potty. This allows them to see if timings of potty or toilet visits need to be adjusted. The Potty Whiz: Potty training log app is good for this[8], or there is an assessment chart available online from Bladder & Bowel UK[9].

- Timings for potty or toilet visits should always follow the last void, rather than the clock.

- Families should be advised that if their child appears to be wet every time they are checked, they should sit them on the potty or toilet every hour and then repeat the baseline assessment once timed toileting is established. If their child continues to appear to be constantly wet this should be assessed by a healthcare professional before moving on. This is particularly important if their child is over the age of five or has a history of urine infections or other related issues. Constipation should always be excluded as it is a common cause of children wetting frequently.

- Social stories can help children become more aware of what is expected of them. These can be personalised and show a favourite character using the potty or toilet as well as the child. The story can also include the reward that is being using for success on the toilet/potty 10.

- Children who are able to help pull their pants/trousers up or down, wash/dry their hands and flush the toilet they should be encouraged to do so. Those that are not able to do this should have the skills introduced using backward chaining (they learn to do the last part of the activity first and then gradually do more, working from the end of the task to the beginning as they make progress).

- Families may introduce playing wet and dry games with toys, pants, flannels etc. ‘Oh, look this is wet, can you feel it?’ and ‘this is dry, can you feel that?’ to help with understanding.

- During this step, families may choose to use washable trainer pants for their children in preparation for step four when ordinary washable pants are worn.

- When the child is successfully passing about half of their voids and bowel motions into the toilet or potty the family should move to step four.

[8] The Potty Whiz potty training log is available at https://play.google.com/store/apps/details?id=app.kidplay.pottywhiz&hl=en_GB&gl=US and https://apps.apple.com/us/app/potty-whiz-training-app/id1493987452

[9] There is an assessment chart available from Bladder & Bowel UK at https://www.bbuk.org.uk/wp-content/uploads/2022/11/Baseline-bladder-and-bowel-chart-paediatric-Bladder-Bowel-UK.pdf and this is included in Appendix Three.

[10] Let’s Talk Visuals at https://www.facebook.com/LetsTalkVisuals/ can make bespoke social stories and picture cue cards.

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

Step Four – Introducing washable pants

- The family must be advised that there may be lots of wetting incidents (small start/stop voids) as their child starts to experience and learns to respond to the sensation of voiding. Ensure that they have plenty of pants, changes of clothes, protective covers for sofas, car seats, pushchair etc.[11].

- Advise the family to make sure everyone who looks after their child knows the plan for the nappy coming off, so they are also prepared.

- The family remove their child's nappy during the day, substituting them for washable pants.

- The family should take their child to the toilet or potty at the same times as they were in step three. As their child's bladder capacity gradually increases with time, they will be able to gradually increase the time between toilet or potty visits.

- Families need to be aware that many children take time to learn to indicate when they need to use the potty or toilet, or to be able to take themselves. A toilet picture, consistent use of a sign, song, or object of reference for the toilet alongside everyone involved with their child's care using the same words for the toilet or potty, passing urine and opening their bowels will help.

[11] Many families chose to use washable pads or disposable puppy pads as these are lower cost, effective and easy to source

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

APPENDIX TWO

Common Myths about toilet training children with learning disabilities

Myth: All children with learning disabilities will have difficulties becoming toilet trained.
Children with learning disabilities are as individual as typically developing children. Although some may experience difficulties, with the right support and approach they can learn the skills for toilet training and many will become completely independent.

Myth: If the child is not verbalising or mobilising independently 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 continued use of pictures and sign language encouraged. The child may also continue to need help and support to access the toilet but can remain clean and dry.

Myth: It is best to wait until children with learning disability 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 difficulties, 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 have never felt wet.

Myth: Constipation is part of having a learning disability and therefore not a big issue.
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 learning disabilities are because of their disability and do not require investigating and treating.
Children with learning disabilities are more prone than their typically developing peers to underlying bladder and bowel problems, including congenital anomalies affecting daytime continence, enuresis and constipation. As a result, every child with wetting and/or soiling problems, including delayed toilet training, should be appropriately investigated, and treated. To not undertake such assessment and treatment for children on the basis that they have learning disabilities is inequitable.

Copyright Down Syndrome UK and Bladder & Bowel UK 2026

APPENDIX THREE

Pad:	Toilet/Potty:
W = wet D = dry B = bowels open M = moist/damp	T = toilet/potty TU = wee on toilet TB = poo on toilet

BASELINE BLADDER AND BOWEL CHART

CHILD'S NAME:______________________________ DOB: __________________

DATE BEGUN: ______________________________ NHS No __________________

	DAY 1		DAY 2		DAY 3		DAY 4		DAY 5		DAY 6		DAY 7	
DATE														
TIME	Pad	Drink	Pad	Drink	Pad	Drink	Pad	Drink	Pad	Drink	Pad	Drink	Pad	Drink
7.00														
8.00														
9.00														
10.00														
11.00														
12.00														
1.00														
2.00														
3.00														
4.00														
5.00														
6.00														
7.00														
8.00														

BASELINE BLADDER AND BOWEL CHART

Information collected on the baseline bladder and bowel chart can be useful to help plan a toileting programme. It can also be used to see how your child's bladder and bowel are working and if there are any problems, such as constipation.

The chart should be completed for at least three full days, or more if you can manage that. These days do not need to be consecutive, but your child needs to be at home for most of the time on the days the chart is being done, as you will need to check their nappy every hour they are awake. Schools and nurseries do not usually have the resources to help. The more days that are completed the greater the likelihood that you will be able to see if there are any patterns to when your child opens their bowels or passes urine. These patterns can be helpful for knowing the best time to sit your child on the potty or toilet when you are toilet training them.

Modern disposable nappies have special highly absorbent granules inside them. This holds the urine within the nappy, so that the layer of the nappy that is next to your child's skin stays dry. This helps to stop their skin from getting red and sore, but it helps your child to feel dry, which makes them less aware of their bladder emptying than they would be if they felt wet. It also makes it more difficult for you to know when they have passed urine.

Therefore, to complete the chart, something is needed inside the nappy to make it easy to see if your child has passed any urine. The nappy may not look wet if they have only passed a small amount of urine. If you put a piece of folded kitchen roll (one that does not disintegrate when wet) inside the nappy, it will be easy to see if they have been wet.

At the first nappy change of the day put a piece of kitchen roll inside the nappy. Then check your child's nappy every hour that they are awake. Record on the chart whether your child had passed any urine by marking W if they were wet, 'D' if they were dry. If your child has had their bowels opened write 'B'.

If the kitchen roll that you put inside the nappy is wet it should be changed, but the nappy can stay on until it cannot hold any more urine or is soiled (i.e. when it would normally be changed). Continue like this until night time. Do not use the kitchen paper inside the nappy overnight.
If your child uses the toilet or potty, then write 'T' in the pad column to show they sat on the toilet or potty. If they manage to pass urine on the toilet or potty write 'TU' (for toilet urine). If they open their bowels on the toilet or potty write 'TB' (for toilet bowels).

Every time your child has a drink then make a note in the drinks column. If possible, also write down what they had and how much. If your child has a tube feed, that should be recorded in the drinks column, with the volume. If your child has a meal, then make a note of that on the chart with the letter 'F' (food).

Bladder & Bowel UK and Down Syndrome UK retains all rights to this document. It may be freely downloaded, printed, reproduced and disseminated in whole or in part, so long as it is appropriately referenced.
Copyright: Bladder & Bowel UK. Registered Charity Number 224742.
Down Syndrome UK. Registered Charity Number 1184564