



STARTING IN A FEW MINUTES AT 15:30

**Improving the lives of babies and children
with special educational needs and disabilities**

19 June 2025

#iHVInsights

www.ihv.org.uk



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Welcome



Make the most of the opportunity



Enjoy the whole hour



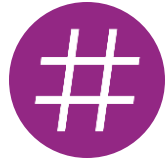
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- Attendance at this event and engagement with the iHV reflection template will support you with demonstrating CPD activities that align to the 2022 NMC Standards of Proficiency for SCPHN Health Visiting.

The Institute of Health Visiting is a charity and centre of excellence for health visiting. Its core purpose is:
To improve outcomes for children and families and reduce health inequalities through strengthened health visiting services

#iHVInsights

Improving the lives of babies and children with special educational needs and disabilities

Welcome

- Dr Karen Whittaker - Education & Workforce Lead, iHV
- Kirsty Jacques - iHV Expert Advisor for SEND

Guest Speakers

- Maddie Rew - Programme Manager (Health Visiting Professional Services), iHV
- Alice Jones Bartoli - Deputy Director, National Children's Bureau
- June Rogers MBE - Paediatric Continence Specialist, Down Syndrome UK

Q&A with Speakers

Close and Evaluation



Maddie Rew

Programme Manager (Health Visiting Professional Services), iHV



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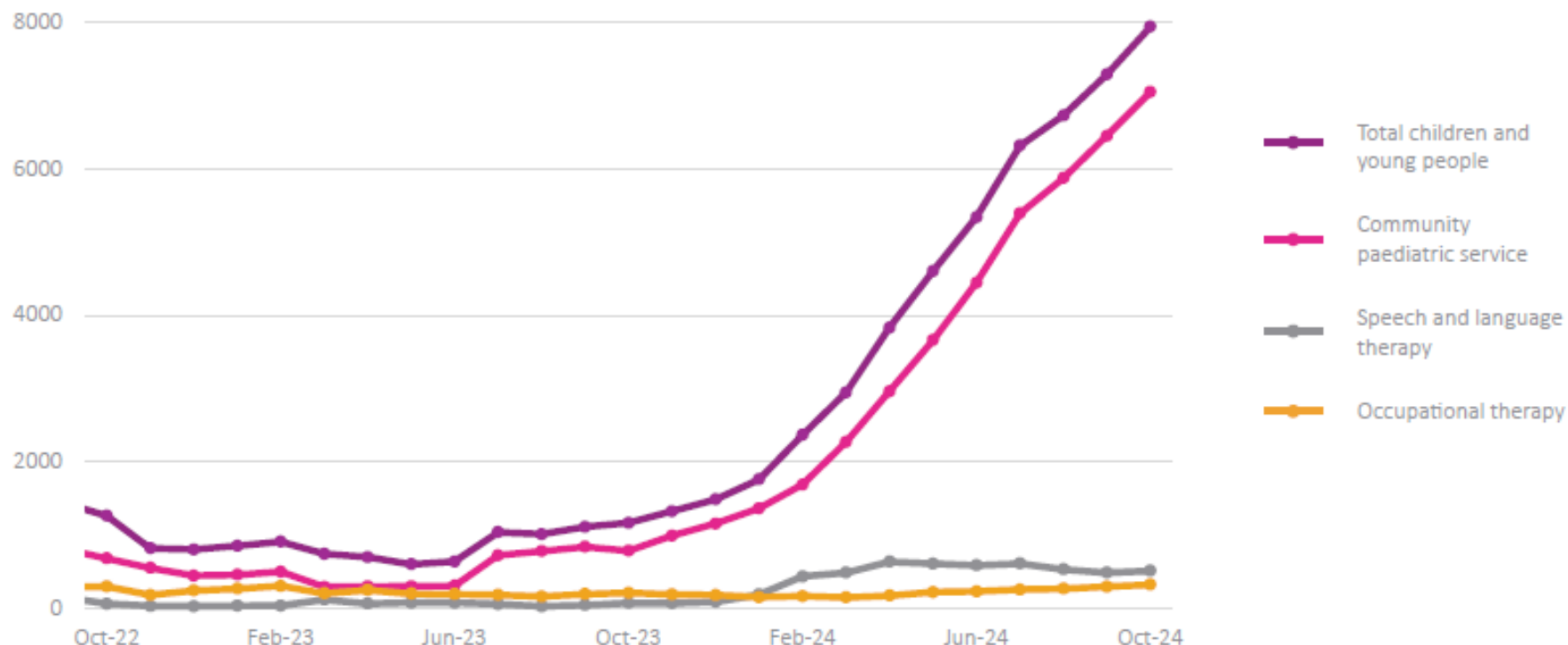


The vital contribution that health visitors bring to solving the SEND crisis

Maddie Rew, Programme Manager (Health Visiting Professional Services, iHV)

SEND Crisis

Figure 2: Number of adults and children waiting at least two years for community and elective hospital services – from October 2022 to October 2024 (Source: Unpublished NHS England data, 2025 – FOI data, Health Service Journal¹⁵, shared with consent)



Hundreds of children with special needs wait a year for support in England

In some areas young people have been waiting more than two years for plan detailing help they require, FOI reveals

- Analysis: responsibilities were heaped on councils as funding shrank
- Special school places allocated on 'very fine margins', twins' father says



Send crisis in England risks creating 'lost generation' of children

Many local authorities facing bankruptcy as government criticised for lack of urgency



The number of children **waiting two years** (104 weeks) or more for a community health service **more than tripled** between February and October 2024, to 7,946; this is many times greater than the waits for elective hospital services.

The demand for SEND support is growing – not just for the 2 million children in England who are known to have disabilities, but for a larger population including those who are waiting for a formal diagnosis or require additional support to thrive.

SEND Inquiry

The **government** is preparing major changes to SEND provision. The SEND Inquiry is in progress.

When adequately resourced, **health visitors** provide an important **part of the solution** in ensuring that families get good, joined up support.

The iHV has set out the role of health visitors in SEND in [its submission to the recent SEND Inquiry](#) with a call to:

- ✓ Prioritise the critical earliest years
- ✓ Maximise the role of health visitors
- ✓ Improve integrated SEND pathways
- ✓ Strengthen the Healthy Child Programme and HV model for England
- ✓ Tackle workforce issues

SEND crisis must be 'first order issue' for new government

Labour has inherited a system on its knees with councils facing bankruptcy, parents forced into court and schools crying out for resources

Institute of Health Visiting's written response to the major inquiry: Solving the SEND Crisis.
Evidence submitted: 2 February 2025

About us: The Institute of Health Visiting (iHV) is an independent professional body, charity and centre of excellence for health visiting – established to strengthen the quality and consistency of health visiting for the benefit of all babies, children, families and communities.

Our evidence is focussed on providing an effective, collaborative approach to SEND provision which keeps the needs of babies, children and families at the centre - improving outcomes and reducing inequalities. We focus on the vital contribution that health visitors bring to solving the SEND crisis. Our response is focused on Part I – we also provide some additional evidence for Part II, III and IV.

When adequately resourced, health visitors provide an important part of the solution in ensuring that families get good, joined up support. The benefits of an effective health visiting service accrue to numerous government departments, contributing to a whole system response to improve SEND provision¹.

Through their **universal reach**, health visitors work with **all** families from pregnancy to school entry. As registered and regulated Specialist Community Public Health Nurses, they are widely **trusted** and their support is welcomed by families. With a **breadth of skills** that straddle child and adult health (physical and mental health), child development, social needs and safeguarding, they can ensure that families get the right support, including during long waits for assessments in specialist services. In the NHS, early senior clinical decision making has been recognised as a crucial first step in effective care planning, identifying those with the greatest need to manage risks, improve outcomes and reduce costs in the long run.

Through home visiting, health visitors see the “whole child” in the context in which they live; this provides valuable insight into their unique strengths and difficulties. During their universal and targeted contacts, health visitors strive to develop relationships and work in partnership with families, to create a personalised plan of care that meets the needs of the child.

Their ability to reach all families is particularly important for those on the margins of society that are often invisible to other services. Through their knowledge of local health systems and wider support, health visitors also play an important brokering role, connecting families to other services and resources to meet their needs. Health visitors have been described by Unicef-UK as the “**backbone of the early years... the safety-net around all families**”².

Part I: Improving support for babies and young children with SEND

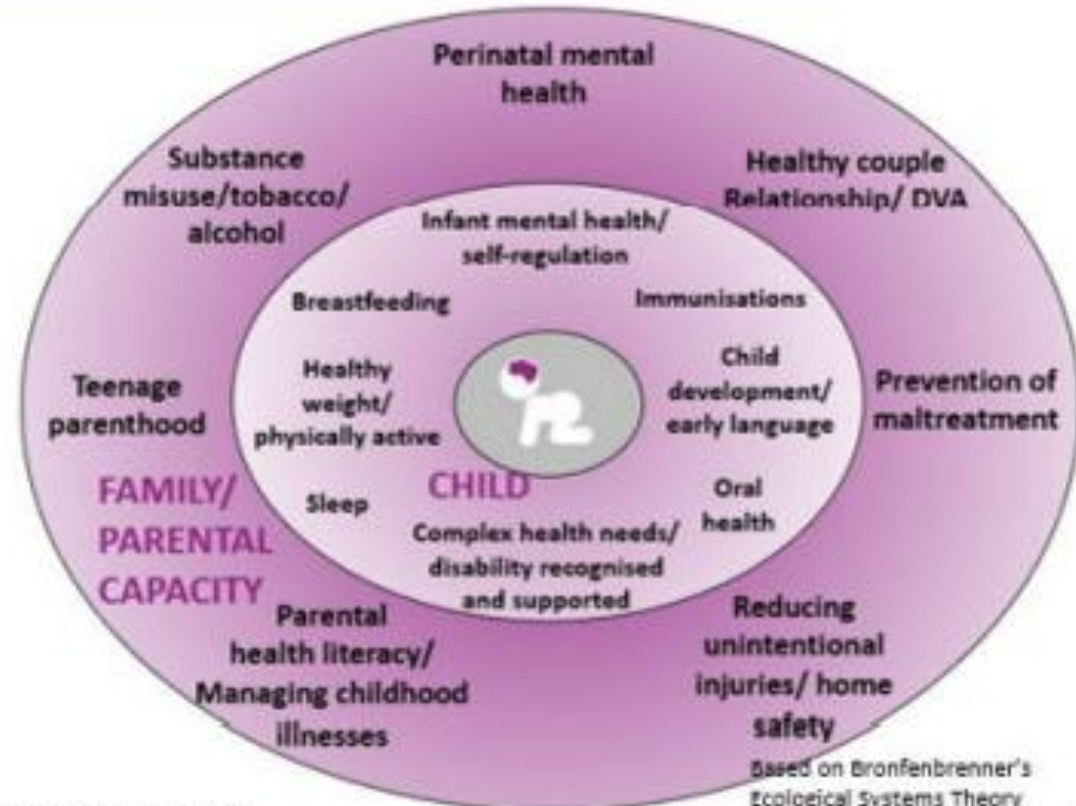
1.1 Outcomes for children and young people with SEND and how these can be improved:

Prioritise the critical earliest years



- The earliest years of life are critical for shaping a child's development.
- Policy “baby blind spot” leads to wasted opportunity for improved outcomes.
- Equal SEND support for children under five as for school-aged children.
- Calls for better integration between health and education policies to address this gap.

Maximise the role of health visitors across an integrated SEND pathway of provision



Supporting all children to have the best life from the start

Improve integrated SEND pathways



MOTOR DEVELOPMENT TOOLKIT

Current referral pathways for SEND are:

- Complex and inconsistent across local authorities.
- Siloed between health and education.
- Delays in speech and language, OT, and paediatrics widen the gap for children.

Integrated Pathways

- ✓ Improve early identification and support for children with SEND.
- ✓ Reduced long-term costs through early intervention.
- ✓ Enhanced outcomes for children and families through coordinated services

Improving SEND provision – [the Cerebral Palsy \(CP\) integrated pathway has been developed by NHS England](#) It provides a blueprint on which to model local SEND “health” pathways for other conditions, with key roles for health visitors in early identification and supporting early assessment/care planning.



Date published: 2 May, 2025
Date last updated: 2 May, 2025

Commissioning framework for children and young people with cerebral palsy

[Publication \(/publication/\)](#)

Strengthen the Healthy Child Programme and HV model for England

- Increase health visitor **workforce capacity**.
- Ensure that all babies and young children receive the **mandated universal Healthy Child Programme reviews**. Increase the number of universal health visiting contacts to eight
- **Strengthen the health visiting commissioning guidance**
- Non-face-to-face contacts should not count as mandated universal health visitor reviews in service delivery metrics
- **Parents want continuity of carer**
- Replace the Ages and Stages Questionnaires with a validated, UK-specific child development assessment tool
- **Strengths-based**, child and family centred services
- Family Hubs and health visitors should work together to **coordinate care**
- **Quality Improvement**



Health visiting contact	England average
New birth visit by 14 days	83%
6-week review by 8 weeks	81.8%
12-month review by 15 months	86.5%
2-2½ year review	78.4%

[Office of Health Improvement and Disparities \(OHID, 2024\)](#)



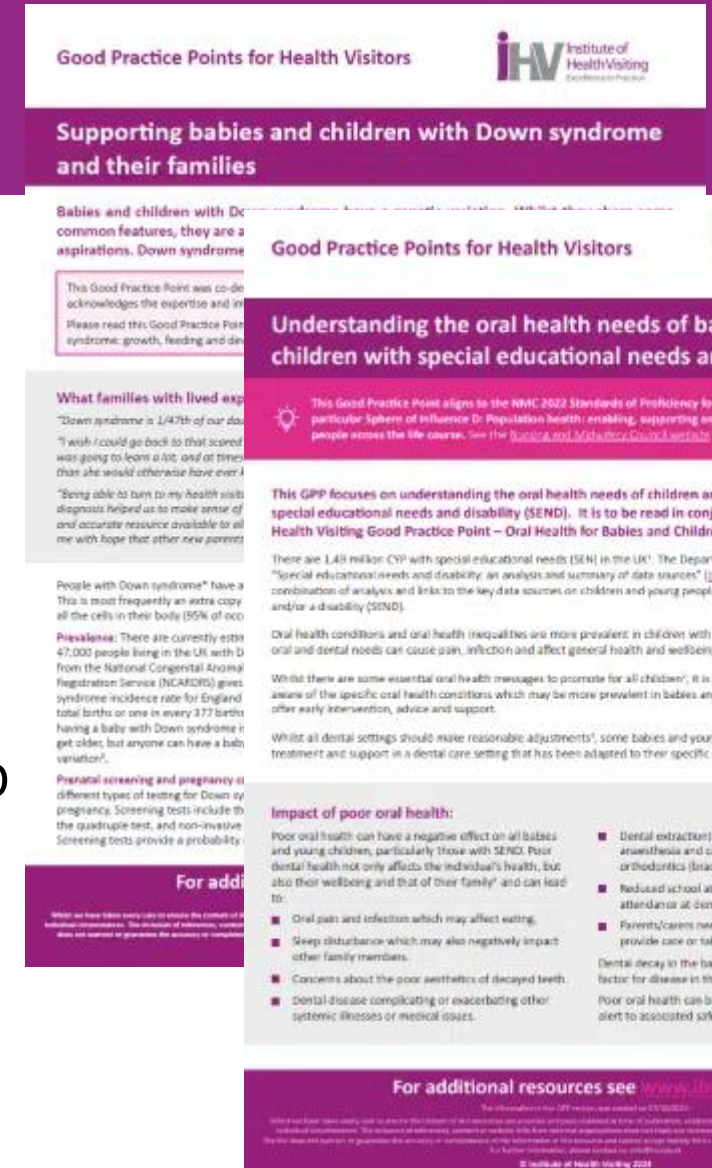
Tackle workforce issue

- Train enough health visitors
- Retain health visitors
- Reform - [Speaking up – Alison Morton gives powerful oral evidence to First 1000 Days Inquiry](#)
- Accurate workforce modelling
- Strengthen health visiting SEND provision including:
 - Ensure all areas have **specialist health visitors for SEND** to provide clinical leadership
 - **Training is essential** to ensure all staff have the right knowledge, skills and competencies to provide safe, high-quality care, meet regulatory standards and keep up to date.



iHV resources to support your practice

- [Good Practice Points](#) for example: Supporting children with Down syndrome: growth, feeding and development, Supporting Gross Motor Development in Babies and Children Under 5 Years
- [Training](#) opportunities including; Changing Conversations: Autism and Supporting Behaviour Ambassadors Training, Genomics Ambassador Training Programme. Coming soon – Motor Development Toolkit.
- [SEND Special Interest Group \(SIG\)](#) if you are interested in joining our SEND Special Interest Group, please register your interest using the QR code.



Next speaker



Alice Jones Bartoli

Deputy Director,
National Children's Bureau



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Improving the lives of babies and children with SEND

A Good Level of Development

Prof Alice Jones Bartoli

Good Level of Development

- The Opportunity Mission, the ambition for the ‘healthiest generation of children ever’ (including strengthening health visiting), the Child Poverty Strategy, and reforms to the SEND system should all incorporate this milestone as a key success measure.

Challenges...

- The focus is narrow – attainment over meaningful progress
- What does it mean for children who may be unlikely to ever reach the milestone?
- Alignment with community priorities and need
- The first cohort to be measured against this milestone are already two years old... what about preventative policy?

The role of Health Visitors

- ... the Strong Foundation
- A foundational role in public health
- A universal
- Vital for perinatal and infant mental health
- Promotion of the home learning environment
- A hub for multi-agency communication

Health Visiting within an evolving system

- Increase in SEND – an increase amongst HVs to consider neurodevelopmental difficulties (children and parents?)
- Increase in early entitlements, 30 hours of subsidised childcare for children aged from 9 months from September 2025
- Are Health Visitors already engaging with early education and childcare settings providing for babies?
- For babies with disabilities and additional needs?
 - Disability Access Fund extended to 2 years and under



Take Aways

- We are arguing for nuance in GLD – a role for progress, as well as absolutes
- Perinatal mental health has a direct route to the Good Level of Development
- Multi-Agency working, including with childcare settings will be important
- Understanding the Local Offer is likely to be of use in helping parents make decisions

Citations

- Condon et al. (2020). Promoting children's health when a parent has a mental health problem: a mixed methods study of the experiences and views of health visitors and their co-workers. *BMC health services research*, 20, 1-15.
- Halpin, J., & Nugent, B. (2007). Health visitors' perceptions of their role in autism spectrum disorder. *Community Practitioner*, 80(1), 18.
- Law et al. (2021). Income disparity in school readiness and the mediating role of perinatal maternal mental health: a longitudinal birth cohort study. *Epidemiology and Psychiatric Sciences* 30, e6, 1–12

Contact: ajonesbartoli@ncb.org.uk



June Rogers MBE

Paediatric Continence Specialist,
Down Syndrome UK



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presentations

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Toilet training - a skill development programme

June Rogers MBE
Independent Practitioner
BA(Hons), MSc

Session overview

- Debunking myths
- DSUK Toilet skill development programme
- Resources and further information





Myths around toilet training

There is often an assumption that :

- Children with ‘additional needs’ will be easier to toilet train if left until they are older
- If the child cannot/does not indicate when they are wet/soiled toilet training is not possible
- You have to wait until they are walking and able to communicate
- Frequent wetting problems are down to their ‘developmental delay’



Other issues

- There is some misconception that toilet training children with ‘additional needs’ will be easier, if left until they ‘are ready’.
- However, if not given the opportunity to sit on a potty or learn about wees and poos even typically developing children will struggle to become toilet trained.
- Waiting for children to be ‘ready’ just does not work!



- **Sarah Turnnidge**
- Role, **BBC News, Bristol**
- 17 August 2024

One in four children are due to start school in September without being toilet trained, a charity has said.

A report by early years charity Kindred found pupils are losing, on average, a third of their learning time each day due to teachers diverting away from teaching and towards supporting children who are not school-ready.



Daily Mail



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SUBSCRIBE
AND SAVE



SATURDAY, JANUARY 4, 2025

By Liz Hull

PARENTS of children who are not potty-trained must come into their school to change nappies themselves, a council has warned.

The rule, which will be implemented when pupils go back to school for the new term on Monday, has been brought in because of the amount of time teachers are spending changing soiled nappies.

Luisa Munro-Morris, director of education at Blaenau Gwent council, South Wales, said the problem was 'adversely impacting teaching and learning'.

The only exception to the policy will be for children who are in nappies or pull-ups for medical reasons.

Teaching unions back the move, but one father, whose three-year-old boy is a pupil, said it was 'discriminatory' and 'unfair'.

'It is obviously a parent's responsibility to potty train but my view, if you look at the literature, is that children hit their milestones at different ages,' he added.

The father also questioned the health and safety implications of leaving a child in a dirty nappy while waiting for a parent to arrive at school to change them. Laura Doel,

Come into school and change your child's nappy, parents are told

leader of the National Association of Headteachers Cymru, said: 'We have had some school leaders reporting that an increasing number of children in school are not always hitting those key milestones before they arrive, including their self-care needs. School

'Still using buggies'

leaders therefore welcomed Blaenau Gwent's decision to intervene on this issue.'

Research has shown that up to a quarter of British children start school without being toilet-trained. But a

recent poll of 1,500 parents by early years charity Kindred found almost 90 per cent felt children should not be allowed to begin lessons until they had learned such a basic skill.

Former children's commissioner Anne Longfield warned in October that the coronavirus pandemic had stunted this year's intake of reception pupils' 'school readiness', with them arriving for school still wearing nappies and using buggies.

She added that parents' lack of access to early intervention services and isolation after their child's birth had impacted their ability to hit key milestones. A report pro-

duced by Mrs Longfield's think-tank Centre for Young Lives alongside Child of the North found a third of children were not considered to be 'school ready' or capable of carrying out basic tasks, such as going to the toilet, dressing, listening, holding a pencil or using a knife and fork in 2022-23.

The research - which looked at Early Years Foundation Stage data on five-year-olds' development in England - also highlighted the postcode lottery of school readiness, with just 59 per cent of children in Manchester being 'school ready' compared with 84 per cent in London.



What research tells us ...

Xing Li et al (2020) **Delayed in toilet training association with pediatric lower urinary tract dysfunction: A systematic review and meta-analysis**

J Pediatr;16(3):352.e1-352.e8. doi: 10.1016/j.jpurol.2020.02.016. Epub 2020 Mar 10.

Geist BK, Bammer-Zimmer R (2023)

Effects of Early Toilet Training and Elimination Communication With Respect to Diaper Types

Clin Pediatr (Phila);62(8):901-907. doi: 10.1177/00099228221145268. Epub 2023 Feb 28.



Toilet skill development programme

- This programme enables children to learn about and develop the necessary skills to enable them to become toilet trained age appropriately
- It starts with early potty sitting – this is NOT potty training at this stage – not unlike introducing a toothbrush when first baby teeth come through
- Formal toilet training and going into pants only happens when the child has developed some awareness and understanding regarding using the potty/toilet

Although we advocate early potty sitting...



Step by step toilet skill development programme





Step by step programme

- Step 1 – getting started and introducing the potty
communicating and talking about wees and poos
- Step 2 – potty/toilet sitting as a routine part of the day
developing awareness and understanding
- Step 3 – timed toileting informed by assessment - making
sense of bladder signals and the need to go to the toilet
- Step 4 – removal of nappy and going into pants!
reinforcing the skills and developing independence



Step 3 Timed toileting

Timed prompting to sit on the potty becomes a routine part of the child's day – no matter where they are!

Reuben 22 months

Toileting games were developed to help raise awareness and understanding





Tommy aged 1 year – sitting on the potty from 7 months



Tommy aged 2 yrs 4 months now toilet trained and in pants

downsyndromeuk.co.uk/parents/toiletraining



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Pants 4 School Programme

Pants4School

Toilet training children with Down syndrome.

 [Toilet Training Group](#)

[Sign up for updates](#) 









Toilet Training Programme	Toilet Training Bootcamp	Toileting Chart
Best Practice Guidelines for Professionals	Toileting Training Videos 	Top Toileting Tips
Facts about Constipation	Constipation Social Post	Toileting Issues (Intimate Care) in Schools and Nurseries
Intimate Care Plan	Constipation issues	Hirschsprung's Disease

Join our Toilet Training Facebook Support Group

A group where parents of and professionals working with children with Down syndrome in the UK, can share advice, experiences, resources and access training and support, around toilet training.

-  A lovely community of parents and professionals
-  Advice and support for mums and dads
-  Up-to-date information
-  Access to resources and training

 [Pants4School Support Group \(0-5 years\)](#)

 [Toilet Training Support Group \(5 years +\)](#)





National toilet training guideline

<https://www.downsyndromeuk.co.uk/docs/All%20things%20toileting/Supporting-Skill-Development-for-Toilet-Training-Best-Practice-Guidelines-for-Professionals.pdf>



Foreword: Alison Morton CEO, Institute of Health Visiting

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.



Resources available on Twinkl

www.twinkl.com/resources/twinkl-partnerships/down-syndrome-uk

pant4school

Toilet Skill Development Programme

DSUK
Down Syndrome UK

twinkl

ink saving Eco

Who one is it if your it's never

regular

regular

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ink saving Eco





Down Syndrome UK: Toileting Chart



Down Syndrome UK: Toilet Training Sequencing Game (Girls)

★★★★★ ∨ 5.0 (1 review)



Down Syndrome UK: Information for Parents

★★★★★ ∨ 5.0 (1 review)



Down Syndrome UK: Pants4School Toilet Skill Development Programme



Down Syndrome UK: Toilet Training Sequencing Game (Boys)



Down Syndrome UK: Intimate Care Plan



Down Syndrome UK: Dress Up For Down Syndrome Poster



Down Syndrome UK: Dress Up For Down Syndrome Fundraising Booklet



Down Syndrome UK: Toilet and Potty Bingo Game



Down Syndrome UK: Dress Up For Down Syndrome Paper Dolls Activity



Down Syndrome UK: WC Dominoes



Down Syndrome UK: Drinks and Bladders Game

Raising expectations!



Posted by a mum on the closed FB group

“I just wanted to share a little moment with you all. Felicity started school in September '24 . When visiting local schools, a headteacher asked, ‘What do you think the chances are of Felicity being toilet trained by the time she starts?’ She couldn’t hide her surprise when I responded, ‘She already is!

All thanks to #pants4school”

Alice - (April 2023)



Pants 4 School is brought to you by DSUK

For more information visit:

www.downsyndromeuk.co.uk



We will aim to answer as many questions as possible during the live session.

Use the Zoom Q&A function

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Over to you!




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Watch #ShapingUs - The Princess of Wales spotlights the vital role of Health Visitors



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Improving the lives of babies and children with special educational needs and disabilities

Future iHV Member Benefit Event Dates



TOPIC	DATE
Practice Education Networking Event	25 June 2025
Special Educational Needs and Disabilities Special Interest Group event	2 July 2025
iHV Insights - Invisible: Exploring Fathers' Mental Health	17 July 2025

All future dates can
be found at:
bit.ly/4enHn2H



Changing Conversations: Autism and Supporting Behaviour Ambassadors Training



1 day programme



Suitable for health visitors and those with a SEND role



Special reduced rate for iHV members



Email:

training@ihv.org.uk

to register your interest

The Ambassador one-day event will enable practitioners to become iHV Ambassadors for Changing Conversations, equipped with relevant knowledge and understanding of autism in the early years to become place-based leaders in raising awareness with peers, colleagues and families.

This programme is underpinned by the voices of parents and people with lived experience, and we are joined by a number of expert speakers.

“The day was well spent. I liked the variations of the presentations; it included everything you would want in a virtual presentation/training.”

Margaret Okiki, Health Visitor Clinical Lead.
Attended training on 3 June 2025

Join us again!



Invisible: Exploring Fathers' Mental Health

17 July 2025 at 15:30

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