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Autism and toileting

Lorraine MacAlister is an autism training consultant for The National Autistic Society. She has delivered training for both parents and professionals on a variety of issues related to autism, including toileting difficulties. She has also recently had an article published in The Nursing Times on toileting problems in children with autism.

Learning to use the toilet, particularly in a way that others see as an appropriate way, can be a real challenge for some children with autism. It is important to recognise that there may be a variety of different reasons why some children with autism find the acquisition of toileting skills difficult, some related to their autism, others related to specific physical difficulties, or a combination of the two.

Common toileting difficulties for children with autism can include:

- difficulties in learning to use the toilet in the day and at night
- knowing when they need to use the toilet
- communicating the need to use the toilet
- being able to get themselves to the toilet
- learning to use different toilets
- sensory and environmental challenges
- wiping themselves
- smearing their poo
- a range of continence specific difficulties including bowel or bladder problems.

It can be a topic that many people still find very hard to discuss, parents may have felt incredible pressure from family, friends and other professionals about addressing toileting and some of the resulting advice may have been unhelpful or even misleading.

There are various characteristics of autism that can lead to difficulties with learning to use the toilet (Wheeler, 2007; Coucouvanis, 2008). Some of the language and communication around toileting can be confusing, many children may not understand what you are asking them to do or could take things very literally, the phrase 'go to the toilet' may only actually be telling them

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to go to the room, not what they should be doing in there. A child may think that you know they have had a wee, may not be aware they should or know how to communicate this.

Some children may not be socially motivated to wear 'big boy/girl pants', may not want to please you by weeing in the right place or understand how pooing in the wrong place can impact on others, they are also less likely to learn new skills by copying other children. A change in routine can be difficult for many and some children gain some skills but have difficulty transferring this knowledge to different toilets. Some have anxieties around using the toilet; think how cleaning product adverts suggest germ monsters live under the toilet seat!

Many children experience sensory differences. For some this can mean they do not register that their bowel or bladder is full or they don't feel the need to go. Some might not be aware of wee's and poo's in their nappy while others enjoy the sensation. Some children may find the bathroom a very overloading room to be in – or they may love it but are more interested in posting things down the toilet or flushing it!

Although it is extremely important to consider the impact of autism on toileting difficulties, it is vital that we also look into whether there are any additional health problems that could be contributing to them. There is a risk when a child has any form of disability that everything can get blamed on that disability, whereas there might be other specific continence issues that need investigating further and treating.

It is important when working with a child with autism to look from both the autism and the health perspective. For example, a child may be in pain from a medical perspective but they either may not be aware of it or may not communicate it. One of the biggest areas of concern that we have found delivering our training to parents and professionals has been the amount of children with constipation that no-one has recognised. As a non-nurse, I've had to learn that just because a child appears to be pooing, doesn't mean they don't have problems with constipation. Many parents and non-health related professionals will need support in understanding this. I often recommend the information leaflets available from [PromoCon](#) and the 'Kids Area' on [ERIC's](#) website (for both children and adults).

There is a temptation to delay toilet training with children with autism, however, clinical experience shows that it is preferable to focus on bowel and bladder maturation when choosing when to begin training (PromoCon, 2011).

Extra preparation can be key to successfully using the toilet and overcoming other continence related issues. It is vital to say that success can be achieved, but that it might take longer and need much more preparation and planning. The earlier you can start with addressing any toileting difficulties, the better the chances of success.

Preparation could include considering choosing what words everyone is going to use, planning a visual routine, getting a child used to going in the bathroom, observing the behaviour they are doing and thinking what alternatives we can provide to replace this.

When beginning to address any toileting difficulties, it is important to talk to everyone involved. Trying to teach any new behaviour needs everyone involved to be clear and consistent, so

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changes need to be implemented when everyone is able to mutually support each other with this. It is also important to look at what else is currently going on for the child.

Areas such as:

- ability to go into the bathroom,
- understanding of what a toilet is for,
- use of rewards,
- ability to cope with changes in routines and
- overall level of anxiety and stress

all need to be considered, and may all be things to be addressed during the preparation.

Starting points may include raising the child's awareness of wee and poo, keeping anything associated with toileting (including nappy changes) in the bathroom, changing the child standing up and put the poo into the toilet afterwards (be aware this may be the first time they see their poo, some children enjoy understanding how the body works, what poo is, and where it goes).

Think about clothing and ease of removal, or whether they need an alternative from the potential sensory input they are getting from wearing a nappy. Making the bathroom safe and comfortable with equipment such as a toilet seat, foot stool, or toilet frame. Practice sitting on the toilet (without expectation to wee or poo) as part of their daily routine. Rewards can give feedback and motivate a child, ensure they are appropriate, immediate, and accompanied with praise and specifically for the toilet. Strategies such as sitting a child on the toilet every 30 minutes can often be very unhelpful, as they simply teach a child that toileting is boring or can encourage them to try and empty their bladder every 30 minutes, which is not helpful.

Many children with autism may find it easier to understand and process visual information, so part of preparation may be to choose visual supports that the child can understand. They can also include words or phrases so can encourage everyone involved to use these! The type of pictures needed will be dependent on the child's level of understanding. Choose pictures, symbols or photo's that the child will understand to help them learn what they are asked to do. The resource [Toilet Time](#) has a range of pictures that can be used with boys or girls and show different aspects of the toileting process.

It can be helpful to try and consider the different sensory systems and the bathroom environment from the child's perspective.

Consider factors such as:

- the toilet flush,
- reflective mirrors,
- cold tile floors,
- noisy fan,
- strong smelling cleaning products,
- splashes in the toilet,

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- introducing a fiddle toy,
- a weighted lap blanket,
- installing grab rails.

Some children enjoy the sensation and texture of poo. If this is the case, there may be another way they can achieve the same experience (e.g. play dough).

Some children may use the toilet for wee's but not for poos; still wanting their nappy on for pooing or using their pants. This is where you may need to use visual supports and rewards to teach them the new behaviour. Your first step with this child could be getting them to go into the bathroom for a poo. They're still doing it in their nappy or pants at this stage, you are gradually moving them towards the new way of doing things. Next steps might then include standing next to the toilet, then sitting on the toilet (still with their nappy on), then gradually loosening the nappy or pants.

When addressing specific continence difficulties such as constipation or bedwetting, there are now specific NICE Guidelines which contain useful information:

- [Constipation](#)
- [Bedwetting](#)

To conclude, it is vital to support children, families and caregivers with clear information about the potential difficulties and the fact many of these can be overcome. Successes need to be recorded and celebrated, with the ultimate goal of teaching a child to be as independent as they are able to be.

Resources

[One step at a time](#)

This booklet and set of tip sheets is for parents of a child with special needs. It guides parents through the process of developing toileting skills and toilet training. Also has an accompanying app.



[Visual Aids for Learning](#)

This website has a range of free downloadable symbols on toileting.

Toilet Time – www.sensetoys.com or www.eric.org.uk

A 10 page laminated wipe-clean flip book containing Velcro backed pictures of children toilet training. These provide a visual sequence for the stages of toileting. Also sell the symbols individually.



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Websites

[The National Autistic Society](#)

[PromoCon](#) – promoting continence and product awareness

[ERIC](#) – Education and Resources for Improving Childhood Continence

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[NICE Guidelines on Constipation in children and young people](#)

[NICE Guidelines on Nocturnal Enuresis, The management of bedwetting in children and young people](#)

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