

Information for professionals and carers: toilet training children with autism and developmental disabilities

Introduction

There are many different ways to toilet train and professionals do not always agree on the best method or the right age at to start. Most children are now toilet training at an older age than in previous generations and professionals who work with children usually recommend that toilet training is not started until children are ready. However, there is no general agreement about what makes a child ready.

Signs that a child should start toilet training are normally said to be when they are able to follow simple instructions, can walk and sit without help; are able to tell their parent or carer that their nappy is full; are able to stay dry for two hours at a time, or during naps; can dress and undress themselves; respond to praise; try to copy parents or older siblings; show interest in the toilet or potty; and/or have reached the developmental stage equivalent to most three year olds. However, children with autism and similar conditions may never show these signs. That does not mean they cannot toilet train.

Children with autism often take longer than other children to learn new skills so need a calm, consistent approach and commitment to continue working with them for as long as they need. It is helpful if everyone follows the same routines and starts the process at the same time. Good communication between family and professionals (e.g. child minders and teachers) is important.

When children are struggling with a developmental skill, they are referred to an appropriate professional as soon as the problem is identified. However, although toilet training is also a developmental skill, children who appear to have difficulty, are often provided with 'free' nappies, rather than assessment and support to attain the skill. This reinforces to the parent or carer that the child cannot toilet train, reinforces to the child that it is acceptable to wee or poo wherever they are, and results in long term social, psychological and environmental issues for the child, their families and wider society. In addition, conditions such as constipation, overactive bladder, or congenital abnormalities affecting continence may be missed. Therefore early assessment and support with toilet training should be offered.

Routines

Routines are important for many children but may be more so for children with autism. This can be helpful with toilet training. However, it is important that all the elements required for successful toileting are followed in the same order, as a sequence. Keeping records of the child's drinks, wees and poos for a few days will provide information about their normal pattern for passing urine and opening their bowels. Charts such as those available on the Bladder and Bowel UK website (in the section on children toilet training) can help with recording. Using the knowledge from the charts, to take the child to the toilet at times when they are most likely to need to go, can help with success.

If children are reluctant to sit, then offering an activity that they quite enjoy, such as watching a DVD, reading a story, singing a song, or doing some colouring may help them to relax and comply. It is important to continue with routine times for sitting on the toilet, building up both the length of time and frequency of sitting gradually, until the child is sitting for long enough to be able to complete a wee or a poo. Initially, there should be no expectation of weeing or pooing on the toilet; they need to be able to sit for long enough first. About one minute for each year of their age is long enough for most children to sit, but it may take some time and practice before they can manage to sit for that long, with some children managing only a few seconds to start with. Visual cues, such as an egg timer, may help children understand the concept of time.

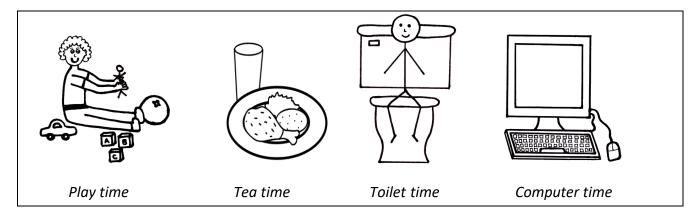
As change can be difficult for children with autism, it might be advisable to go straight to the toilet, rather than using a potty. However, most children will need an insert seat and footstool to ensure they are able to sit comfortably and to feel safe and stable while on the toilet. Both their hips and knees should be at about 90 degree angles.



Understanding and Communication

Many children with autism are visual learners: they understand and learn more easily if pictures are used to help explain what is required. Social stories may be personalised and can be used at a time when the child is relaxed, to introduce what will be expected. The social story may be used on a daily basis before toilet training is introduced and then used before the child is taken to the toilet.

The story should have simple words, with one step of the routine on each page. The same pictures may also be used for visual cues.

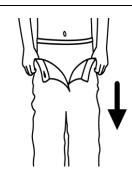


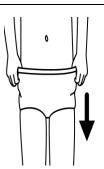
Examples of pictures that would help a child understand that toilet time comes after tea, but before they are allowed to play on the computer.

There is an example of a social story 'Talk about going to the toilet' available on the Bladder and Bowel UK website at <u>www.bladderandboweluk.co.uk</u> (in the children, toilet training section).

PECS (picture exchange communication systems), photos, or other pictures, such as the ones available on the Do 2 Learn website, (http://www.do2learn.com/ - used above and below), can be used to give the child an understanding of the toileting process. Special schools may already use picture communication systems and they may be happy to help produce social stories or sequences for their students. The same pictures as are used for the social story may be used to explain the sequence for toileting, and as reminders for children once they start to become more independent:



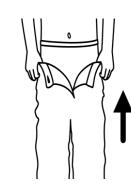








Sit on the toilet



Go to the toilet

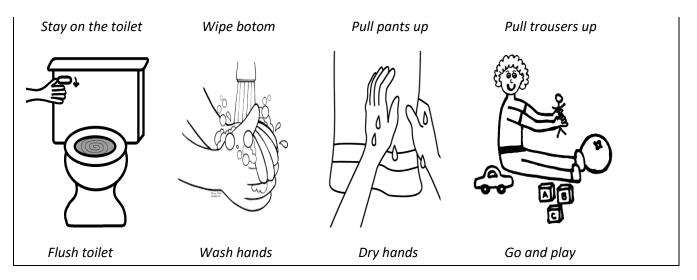


Pull trousers down



Pull pants down

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Familiar communication tools help the child understand what is expected of them, reduce anxiety and may prevent difficult to manage behaviours.

The pictures should be adapted to suit the child's individual routines, illustrating each stage of the process. The child should be shown the pictures before they start the routine, but they should also be displayed (at eye level if possible) in the bathroom, so that they can be used as reminders.

If children use picture cues, they need these at school and when away from home, as well as at home. The pictures will also help other adults who look after the child to ensure the child does things in the same order when with them, as they do at home. This may reduce confusion or anxiety.

When the child begins to use the toilet independently, they may find it difficult to ask to go. Having a picture card available for the child to communicate that they want to use the toilet may help prevent accidents.

Instructions

Many children with autism interpret things in a very literal way. Therefore they need to be given very clear, precise instructions. For example, if a child is just told to 'wipe your bottom', they may not realise that they need to use toilet paper. If told to 'get some toilet paper and wipe your bottom', they are being given two instructions at once, and not being told how much toilet paper they need. The child may find it easier if they are told take three pieces of toilet paper and then told / shown how to wipe their bottom.

The environment

The bathroom needs to be calm and quiet. It is important that the child's needs are considered before starting to introduce them to toilet training. They should feel comfortable and stable on the toilet with an insert seat, to make sure they can sit securely and a foot stool, to ensure their feet are on a firm surface. Some children might also need a rail to hold onto. If they have mobility difficulties, problems with balance, or severe sensory issues, then occupational therapist assessment is advisable.

For children who are reluctant to go into the bathroom, think about what might be causing the problem: if they do not like the feeling of the flooring under their feet, socks or slippers might help; if they do not like the sound of the extractor fan, it may need to be turned off; if they find bright lighting upsetting they may be helped by having a dim light in the bathroom.

There are many objects in the bathroom and some children find these distracting. Putting things that are not needed for toilet training out of sight can help e.g. remove make up, toothbrushes, toothpaste and laundry, or put them in a cupboard.

Some children like the feeling of having their nappy on. It is warm and firm. Alternatives to this, such as a weighted blanket or warm hot water bottle to put on their lap may encourage them to sit.

Rewards

Rewards help to reinforce behaviours that are wanted. Children with autism need a reward when they are first learning to sit, with no expectation of them weeing or pooing at that point. When they are doing this successfully, then rewards should be used when they have managed to wee or poo in the toilet and completed the toileting process. Some children will need the reward as soon as they have weed or pooed, even before they have got off the toilet for the first few times, to know what they are being rewarded for. The right reward will depend on the child's preferences e.g. a chocolate button, or time playing on an electronic game. Praise needs to be used with the reward. However, the child needs to be told exactly what they are being rewarded for: 'Well done Joe, you weed in the toilet'. The reward should only be used for toileting and its use should be avoided for three or four days before toilet training is started.

Once the child is regularly using the toilet to wee and poo, the frequency with which the rewards are given should gradually be reduced, but the use of praise should be continued.

Going out

Introducing children to different toilets early is helpful. They will need their picture cues, if these are used, as they help reduce anxiety. However, some children find public toilets difficult. Unfamiliar smells, the sudden or unexpected sound of another toilet flushing, door banging, or loud hand driers can be upsetting. Disabled toilets tend to be quieter and more spacious, but may need a RADAR key for access. These can be purchased online from Disability Rights UK: https://crm.disabilityrightsuk.org/radar-nks-key

Having picture cues with the different things that are found in public toilets can help to prepare children. Wet wipes might make hand washing easier and having a towel from home can help with avoiding hand driers.

Making progress

For many children the last stage of toilet training is being able to tell their parent or carer when they want the toilet. Children need a way of doing this, particularly if they do not talk. As the child becomes better at letting parents or carers know they want the toilet, either verbally, using sign language, or showing a picture, the parent or carer should start to reduce the number of times they remind them to go to the toilet. If children are always reminded to go to the toilet they may rely on this, rather than listening for their bladder or bowel to tell them when they need to go. They are then more likely to have accidents if the parent or carer forgets to remind them, or are not with them.

Dealing with difficulties

Many children with autism have no problems with learning to use the toilet once they understand what is expected of them and have practise with rewards for getting it right. However, some children do have difficulties. These may often be related to a change in routine that they find difficult to understand and therefore they become anxious and upset. Using stories, pictures, or photographs before introducing any new routines can help make things predictable and less frightening.

Some children are frightened of sitting on the toilet. Making sure they have stools or footrests and an insert seat so they can sit securely will help. Some children may also need a hand rail, or a little table that fits over their lap to make them feel safe. The table can also be used for activities to distract them while sitting. Using calm music and a quite relaxed manner will help the child feel safe and supported. If they are very sensitive to touch, they may benefit from a soft padded insert seat.

Some children are frightened of the flush on the toilet, while others want to flush several times. Using pictures that reinforce the toilet is to be flushed only once, and then only after a wee or poo can help. For children who are frightened of the flush, flushing only after the full routine is finished and the child is at the bathroom door might help. Gradually encourage the child to be further into the bathroom when the toilet is flushed.

Some children resist wearing pants. Many children with autism are very sensitive to textures and pressures on their skin. They may find the fabric of the pants or labels in them uncomfortable, or they may just like the warm, padded, firm feel of the nappy which has been part of their lives since birth. If this is the case putting pants under the nappy and then gradually cutting away small parts of the nappy could be tried. Start by cutting away the part that the child is least concerned about and then gradually increase the amount cut away. Using pants for short periods of time each day and then gradually increase the time of wearing of pants may also be helpful. Using pictures to show them when they will be wearing the pants and rewards for keeping the pants on may make the transition easier.

For children who will sit on the toilet but will not wee or poo there, then try using clear pictures and stories to show them what is wanted. This could be tried for a few days at times when they are relaxed and comfortable, and then show them the pictures when they are on the toilet. Increasing their drinks and taking them to the toilet a few minutes after each drink could also be tried. Taking them to the toilet at times when they are most likely to need to go (e.g. after meals or drinks, or at times indicated from record charts done before starting toilet training), making sure the bathroom

is calm and relaxed with parents or carers keeping as quiet as they can, using a quiet voice to talk may help. The child needs to sit for long enough to relax.

Some children will smear poo. This may happen because they like the feel of the poo, or it may happen because they do not realise they are meant to use toilet paper to wipe themselves. Providing clear picture cues of what is expected, making sure that the toilet paper or wipes are comfortable and easy to use can help. Some children find wet wipes or warm wet cloths easier to use. Make sure the child is helped with wiping, with a hand over theirs, until they are able to start doing this for themselves. If the child has smeared, using the least possible interaction with the child during clearing up is often helpful. If they are smearing because they like the feeling, giving them the opportunity to play with sensory toys such as playdough, finger painting or textured toys may be beneficial.

Making sure there is good communication between home, school and other places where the child spends a lot of time, will help children transfer their new skills to different places.

Conclusion

Many parents worry about toilet training and professionals sometimes give different advice, which can be confusing. Parents and carers are often advised to wait until children are showing signs of being ready to toilet train, before starting. However, many children with autism and developmental disabilities will not show the usual signs, but are able to toilet train with a calm, consistent and sustained approach. There is no reason why building the skills for toilet training should not be started when children are around two years of age. For children who struggle there should be an early referral to a health care professional who is able to provide appropriate help and support.

Additional resources

There is more information about toilet training on:

The Bladder and Bowel UK website at: www.bladderandboweluk.co.uk

The Autistic Society website at: <u>http://www.autism.org.uk/living-with-autism/understanding-behaviour/toilet-training.aspx</u>

Do 2 Learn picture cards available from: http://do2learn.com/picturecards/printcards/selfhelp_toileting.htm

Victorian Continence Resource Centre, One Step at a Time Easy English Toilet Training Guide for Boys available from: <u>http://www.continencevictoria.org.au/wp-</u> <u>content/uploads/2015/06/EasyEnglishBookBoys.pdf</u>

Victorian Continence Resource Centre, One Step at a Time Easy English Toilet Training Guide for Girls available from: <u>http://www.continencevictoria.org.au/wp-</u> <u>content/uploads/2015/06/EasyEnglishBookGirls.pdf</u>

Some schools may have access to picture communication cards and may be happy to help with personalised social stories and picture sequences for their students.