



Cerebra

Positively Different

Toilet Training for Children with Autism and Intellectual Disabilities.

Foreword

This briefing is based on work by Dr Sue Bettison, an Australian research and clinical psychologist who has an international reputation in the fields of intellectual disability and autism spectrum disorder. Her book, released at the end of 2011, called, "Toilet Training for Children with Autism or Intellectual Disabilities"¹ covers both sets of disorders and a very wide range of toileting problems and procedures to correct them. The book contains much of Bettison's collected wisdom from many years of research, clinical practice, and collaboration with parents and others working with children with developmental disabilities.

Background

Children with developmental disabilities are not all the same and neither are their toileting difficulties. Toileting problems can have a number of different causes and as a result require a range of approaches to manage and resolve issues. Children with neurological conditions can sometimes find learning to use the toilet more difficult than typically developing children as the result of physical, behavioural or sensory differences, as well as the learning difficulties which are part of their developmental disability. It is important to note that the majority of individuals with intellectual difficulties will become self-toileting by adulthood.

(Please note, this information deals with daytime wetting and not bedwetting or night-time enuresis)

Dr Sue Bettison



Basic toileting function

Babies are born with a double reflex operating in the bladder and bowel. A reflex is an automatic response to a stimulus or event; in the case of bladder and bowel function, the stimulus is a feeling of fullness which triggers contractions in the bladder or bowel wall and at the bladder or bowel opening so that waste can be forced out. To gain control of both bladder and bowel, children need to recognise the sensation of fullness, override the muscle reflex and learn when and where it is appropriate to wee and poo. As the bladder and bowel grow, increasing amounts can be held before a feeling of fullness leading to a less frequent need to use the toilet. As children get older, they also learn to plan ahead and therefore go to the toilet, for example before going out, even though the bladder may not be full. **Effects of developmental delay on toilet training**

Developmental disabilities often consist of a number of separate problems, many of which can interfere with learning. Generally, the more severe the intellectual difficulty, the more trouble the individual has with learning self-toileting. In addition to learning difficulties, a number of other issues could be preventing a child from developing the skills necessary for successful toileting including medical problems or physical, behavioural or sensory differences.

Medical or physical issues

Although children with special needs are more likely to have medical problems than typically developing children, these problems are not a factor in most cases of toileting delay. If there is any cause to think there may be a medical problem, this should be discussed with a healthcare professional. The following need to be considered when undertaking toilet training:

Bladder or bowel infection

Any infection in the bowel or urinary tract can have an effect on toileting, causing a more frequent need to wee or poo, making it impossible for a child to learn bladder or bowel control.

Constipation or diarrhoea

Constipation can be caused by diet, low fluid intake, some medications or lack of exercise and diarrhoea by diet or a food intolerance such as coeliac disease (intolerance to wheat). Many children on the autistic spectrum have problems with frequent, unformed poo and some parents have found that a diet free of casein (found in dairy products) and gluten (found in certain grains) helps with this. Psyllium powder (available in chemists) can also help to create

properly formed faeces when taken as a supplement. Any dietary changes should be discussed with a healthcare professional.

Spinal cord dysfunction

Sometimes damage to the spinal cord and/or nerves attached to the spinal cord prevents messages passing to and from the bladder or bowel and usually accompanies some form of cerebral palsy. As the sensation of bladder or bowel fullness is an essential stage of self-toileting this can cause delay in learning to self-toilet, but by learning to make regular trips to the toilet, accident-free toileting can be achieved.

Behavioural issues

Resistance to instruction or change

Some children with special needs do not like being told what to do by another and may throw temper tantrums when asked to do something. This can be extremely frustrating for parents and carers and put strain on the parent/child relationship, turning toilet training into a bigger issue for the family. Children with certain conditions may also find any kind of change in their habits or routine difficult to deal with and so resist coming out of nappies and using the toilet.

Dependence on others and lack of confidence

Many disabled children remain dependant long after other children are enjoying doing things for themselves. This can be the result of many experiences of failure, a shy personality, or simply being used to having everything done for them. These children resist being trained to self-toilet and may develop the ability to hold on but will not take themselves to the toilet or let anyone know they need to go.

Reduced social understanding

For some children, particularly those with reduced social understanding, a lack of motivation to be like everybody else can delay self-toileting. Similarly, some do not learn by copying others which is an important part of learning to use the toilet appropriately. If going to the toilet means taking a break from playing or watching television, many children (including typically developing ones) see it as an annoying and often unnecessary interruption! There might also be other,

seemingly more important things happening around the child at any stage of the self-toileting process which are too much of a distraction to carry out the tasks successfully to the end.

Sensory issues

Sensitivity to sound or smell

Many children with special needs, especially those on the autistic spectrum, have problems with sensory information and are either overly sensitive to smell, sound, light and feeling or otherwise do not respond to what they feel, hear, see or smell. Because of the number of sounds, smells and sensations involved in using a toilet, for example, a toilet flushing, harsh bathroom lighting or the feel of the toilet seat on the skin, sensitivity to a particular aspect can be a problem.

Inability to recognise sensations

These sensory problems can also often get in the way of a child's ability to feel bodily sensations, including bladder and bowel sensations and may affect the way an individual understands what they are feeling. Many young children, both disabled and typically developing, can find it hard to tell exactly where on their body they are feeling something and this includes the sensations needed for self-toileting.

Sensory overload

In addition to general confusion about sensations in the body, some children may not always understand certain sensations if they feel overwhelmed by visual information or sounds changing around them. For example, a child might be able to recognise the need to use the toilet when focused and relaxed, but fail to notice when absorbed in a television programme or out in public because of very exciting or upsetting sensory stimuli.

These distractions can also interfere with the steps involved in toileting if the child is not able to fully concentrate on completing the sequence in the right order, for example, being able to tell the difference between pants half up or half down.

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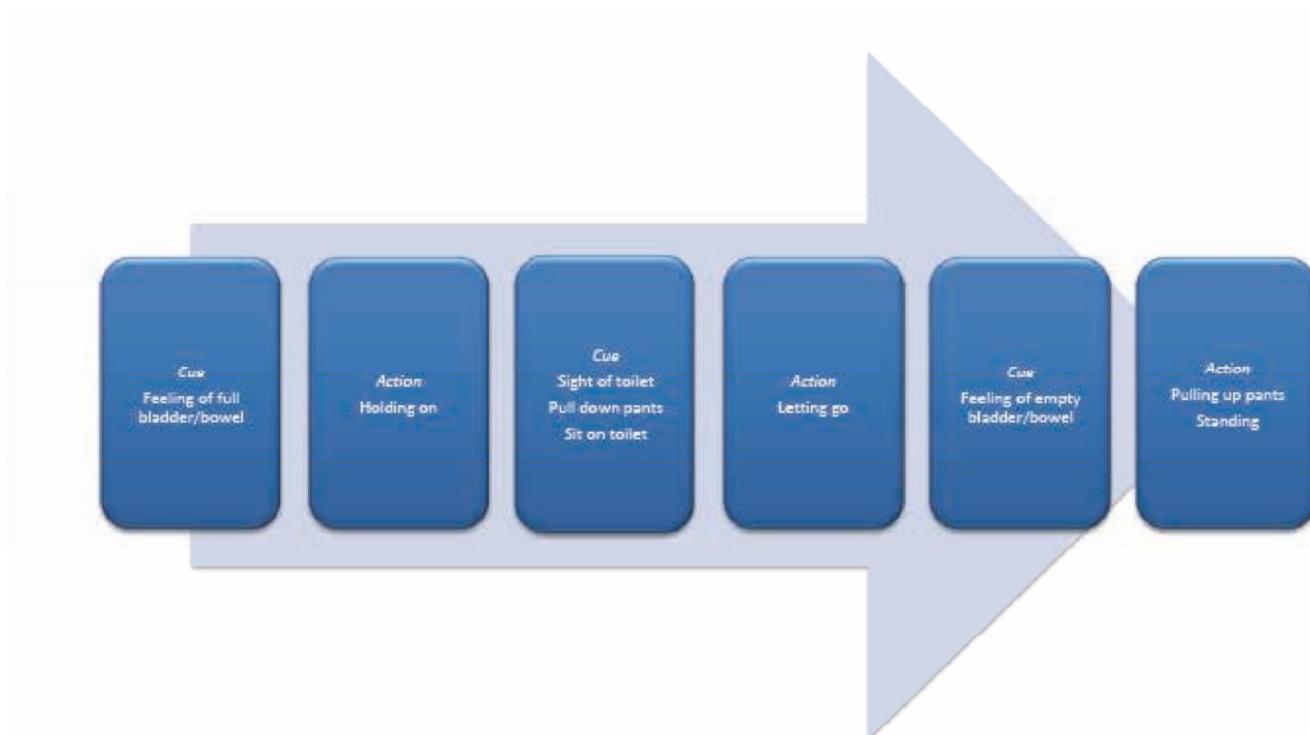


Figure 1 - Breakdown of tasks involved in self-toileting

Sequence of skills needed for self-toileting

The above diagram shows a simplified version of the skills needed for toileting and the fixed order in which they need to happen, as observed by Dr Sue Bettison (2010). By breaking down each cue and action into separate stages, it becomes easier to identify which skills a child already has and which stage is causing a problem. Knowing how many different skills are involved turns the task of toilet training into a series of manageable steps and also reveals why self-toileting can prove to be such a challenge for some individuals. It is possible to break each step down into smaller units, for example the action of pulling up pants, if this is where the problem lies.

Wiping, flushing and hand washing can be introduced once bladder and bowel control are established.

Assessment

Before beginning a toileting programme, it is essential to know what abilities your child already has and which area could be causing a problem. Observing your child for a few days with the sequence

of tasks (fig.1) and the following questions in mind can reveal whether there are already essential toileting skills being used and any possible difficulties:

- How often does he/she wee or poo and how much?

(More than eight wees a day shows that your child never holds on and indicates low bladder capacity or a medical problem such as a bladder infection or abnormality. Several bowel movements a day could indicate a medical problem such as diarrhoea. Bowel movements that occur only every few days could indicate constipation).

- Does he/she indicate an awareness that he/she needs to go?
e.g. by saying, hiding or crouching, crossing legs or holding crotch?
- Are there any signs that he/she knows that weeing or pooing has started or stopped?
- Does he/she ever use the toilet without being told to go?
- If he/she has an accident in the pants, is there a large or small amount?
- If using the toilet, how long does it take for him/her to let go and how much?
- How much help does he/she need to sit on the toilet and pull pants up or down?
- Does he/she always become upset/resistant at the same point in the toileting process?
- What food, toy or activity does he/she particularly like and make an effort to get?

The answers to such questions should rule out any medical problems and help to establish how much control a child has over their bladder and bowel, e.g. if he or she has an awareness of needing to go, is able to control how much and when to let go. It should also indicate any trouble with understanding the sequence of skills needed, particular sensory aspects of using the toilet and what rewards could be used to motivate your child to use the toilet. **Deciding on and implementing a training programme**

Families with disabled children should not feel under pressure from others to toilet train their child and should only do so when they feel ready. The decision to try toilet training should be made when both parent and child feel that they are relaxed and have the time to dedicate to it.² Any tension or frustration resulting from unsuccessful attempts to toilet train can sometimes make toileting into an even bigger problem and have a negative effect on both parents' and children's confidence and family

relationships. If your child shows no bladder or bowel awareness when you decide to begin toileting, as long as he or she is over four years of age, a toilet training programme usually creates awareness.

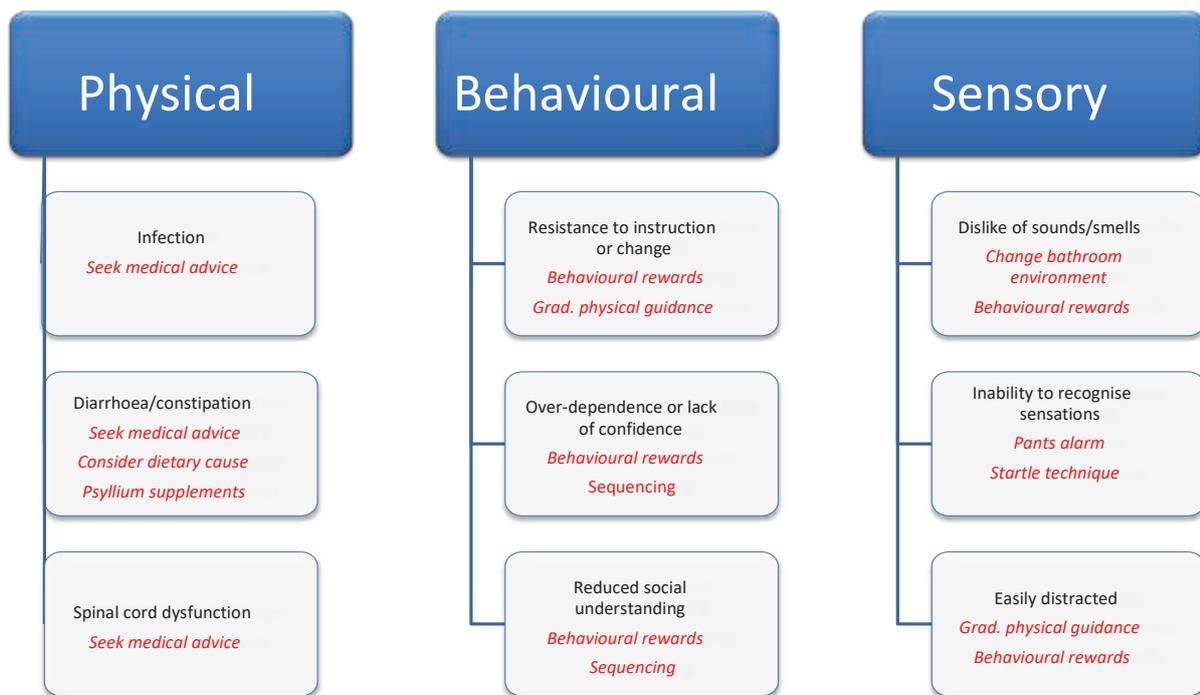


Figure 2 – examples of toilet training techniques for different physical, behavioural and sensory problems – see next page for details.

Toilet training techniques

There is no one procedure or technique guaranteed to work but understanding how your child learns is essential to applying any programme successfully. Different methods work for different people under different circumstances and often a combination of approaches is required before an individual is able to acquire each skill. Below are a number of tried and tested techniques which may be useful.

Giving your child extra fluids during a training programme can be helpful as this can increase the frequency of needing to wee as well as strengthening the feeling of fullness and so give more opportunity for the child to learn.

Pants alarm

For children who are unable to recognise the sensation of a full bladder or the feeling of beginning to wee or poo in their pants, pants alarm devices are available (see Resources, below). The alarm makes a pulsing, beeping sound as soon as the first two or three drops of wee come into contact with the pants and so alerts you that the child needs to go to the toilet. This is useful during training, even if your child is at least sometimes aware of the sensations of fullness. It also helps alert your child to the sensation of a full bladder so that the sensation can then be tied into the toileting sequence.

Startle technique

If you know your child is about to wee or poo (by recognising a particular behaviour for example), or has already started (as indicated by an alarm), the startle response can be used to prompt the tightening of the perineal muscles to stop them going in the wrong place. When anyone is startled, all muscles in the body tighten initiating the 'fight or flight' response. This tightening of muscles can hold back the wee long enough to get the child to the toilet for training. The startle used can be as simple as rushing to your child and shouting 'STOP' - enough to startle but not frighten.

Copying

As mentioned already, some children do not learn by copying, but for many others modelling behaviour on those around them is a valuable lesson. If the other toileting tasks have been learned, such as holding on and letting go, then spending time watching others using the toilet appropriately is sometimes the only training procedure needed to achieve self-toileting.

Behavioural rewards

Another effective procedure is the positive consequence or reward, especially when toileting problems are due to resistance to change or following instructions. A reward has to be strong enough to lead the individual to perform the act again in order to get hold of it and must only be given when that particular act is performed. This can be a tricky area for many children with neurological conditions as responses to standard treats can be unconventional and unpredictable.

Although star charts can be effective for typically developing children, the distant promise of a reward can be too confusing or just not enough to motivate a child with special needs, particularly if there is no social motivation to be like everybody else or to please others. If

possible, try to think of something which your child will value above anything else, for example, tearing paper, popping bubble wrap or even crouching quietly in a corner. The reward needs to be immediate and preferably something which can be ongoing— a one off prize such as a DVD or book may not be enough to make a child perform an action enough times for it to become a habit.

Remember also that any interaction needs to be suitable for the individual child. Where some may respond well to cheerful or noisy praise, others might prefer whispers or more slow, subtle reinforcement.

Punishment

Although toilet training can often be frustrating and tiring for parents and at times it may seem that a negative reaction is effective in discouraging behaviour, punishment is not recommended for a number of reasons. Firstly, it only teaches the child what should not be rather than showing what should be done which leaves the child unsure of how to behave. Children with certain conditions can also sometimes react unusually to some forms of punishment and actually try to make it happen again because some aspect of the punishment functioned as a reward for them, e.g. a facial expression or noise could be exciting or funny for them. Punishment can also cause many feelings of guilt or negativity for both parent or carer and child and so should be avoided if possible to stop toileting putting extra pressure on the family.

Sequencing

To teach individual toileting skills, intensive training uses 'backward chaining' to ensure that each step in the sequence becomes automatic. In this method the last task in the sequence is taught first, e.g. pulling pants up without the first steps being required for success. Starting to train at the end of the sequence means that the action can be performed each time (even when a child has an accident, missing the initial stages) and that a reward can be given at the same point of the sequence each time. Many children become upset when a reward they are expecting is stopped and with backward chaining, the reward always occurs following completion of the last task. Once the final task is learned, the one before can be taught and then both tasks are performed together and by the end of the process, the entire toileting sequence is being performed competently and then rewarded.

Graduated physical guidance

Many people with special needs do not know how to move to achieve a given result. They do not explore and try things and so do not build up a range of skills to use in different tasks. Graduated physical guidance (Bettison 1982) enables a parent or carer to move a learner through the

performance so that the movement is practiced, without the learner needing to move by him or herself. Children who resist doing things when asked can gradually relax and accept the task as their own and begin to understand what a particular movement can achieve, e.g. sitting and remaining sitting on the toilet until toileting is finished.

If the child does not begin the movement after an instruction or prompt, try to firmly but gently guide them through the correct motions. The aim is to always give as little guidance as possible, so that the child is able to learn the movements without help, and to carry on the guidance until it is not needed. Any resistance to the movement should be blocked until the child is relaxed and still and then movement can be started again – this may take a few minutes in early training. Graduated physical guidance needs the parent to sense when the learner is making the correct movement independently in order to release control but then to stay close in order to guide once more if the incorrect movement occurs.

This method is effective for children who have trouble understanding and organising the learning of their movements and allows a parent to guide without force in order to focus on a task and build confidence without the confusion of constant talking. **Bowel movements in places other than the toilet**

Bowel control can be difficult to change because, unlike bladder control, an individual can hold on for days. The infrequency also means there are fewer opportunities to learn to use the toilet and to be rewarded for the behaviour. Many children, especially those with autistic tendencies have a very rigid attitude towards where and when they will go for a poo. Some insist on hiding to go and others will only poo in a nappy or pull-up – hanging on to the habit of babyhood because of the need for a familiar routine.

In some cases, the use of nappies can be gradually faded out by persuading a child to sit on the toilet whilst wearing a nappy so that he or she accepts that the toilet is the appropriate place and is rewarded for this behaviour. Once the child is happy with this, some of the nappy can be cut away so that the poo falls into the toilet and the child is rewarded. Gradually more of the nappy can be cut away and the child rewarded each time until the child accepts using the toilet without the nappy.

A more extreme measure for teaching bowel control involves inserting glycerine suppositories into the child's bottom to make a bowel movement happen. This is useful if a child does not have predictable bowel habits as it makes it possible to introduce one or more of the other training techniques, such as rewards, to make doing a poo in the toilet part of a child's daily routine. If using suppositories, it is essential to read the instructions thoroughly or if unsure

ask for advice on how to use them effectively. Although not harmful if used properly, this experience is not a pleasant one for parent or child and should only be considered if other techniques have failed.

An example of a toilet training programme using the above methods

To begin, the child should be given as many drinks as possible, up to 4 cupfuls. As soon as the child has finished drinking, a timer is set for half an hour, the pants and a pants alarm are put on and normal activities of the day are resumed. This schedule of half-hourly drinks should occur throughout the training period, until about an hour before training is finished for the day. Training should occur for a minimum of 4 hours every day. The longer training occurs each day the sooner successful self-toileting is reached. As soon as the pants alarm sounds, the trainer rushes to the child, shouting 'stop' loudly enough to startle him or her, but not enough to be frightening. Some children with hearing impairments were startled enough when their parents rushed at them and grabbed them. This required staying fairly close to the child during training. The child is then rushed off to the toilet, with graduated physical guidance as the teaching technique to assist the child's learning of the rest of the sequence of toileting skills. No verbal instructions are used other than the startle technique.

'I am the mother of Mary, an 8 year old girl who has autism. We have known Dr Sue for some time. She and I together tried a number of procedures to overcome Mary's sensitivities, obsessions and distress when we tried to teach her the toileting tasks. First we ended up giving her psyllium each day in small amounts in several small drinks one after the other; the only way she would take it. Once her bowels were functioning normally we began the programme and had to keep introducing new procedures to counteract many problems. We developed a way of holding the back of her clothing and running to get her into the toilet before she could drop to the floor. Within a few days Mary was taking me into the toilet as soon as the pants alarm sounded. Then we had to use backward chaining to teach pants up and down. It took a long time with many more special procedures to counteract her changing obsessions before she was independent, and we had a couple of periods of retraining. However, Mary is now fully independent except when her anxiety is extreme'.

This guide is no substitute for specialist advice. The information provided by Cerebra is for information purposes only and is not a substitute for medical advice or

treatment for any medical condition. You should promptly seek professional medical assistance if you have concerns regarding any health issue.

References

- (1) Bettison, S. (2011) Toilet training for children with autism or intellectual disabilities. To purchase a copy of this book visit: www.learn2do.net/bookstore/toilet-training-children-autism-or-intellectualdisabilities
- (2) Eric (2012) Toilet training tips for children with social learning difficulties. Available from www.eric.org.uk

Resources

Cerebra Lending Library - Toilet training for children with autism or intellectual disabilities. Available for loan. To borrow a full copy please visit:

Website: www.cerebra.org.uk or call the helpline on 0800 3281159.

Do2learn – Printable picture cards – ready to use communication tools to help your child develop toilet training skills as well as other daily living and social and behavioral skills.

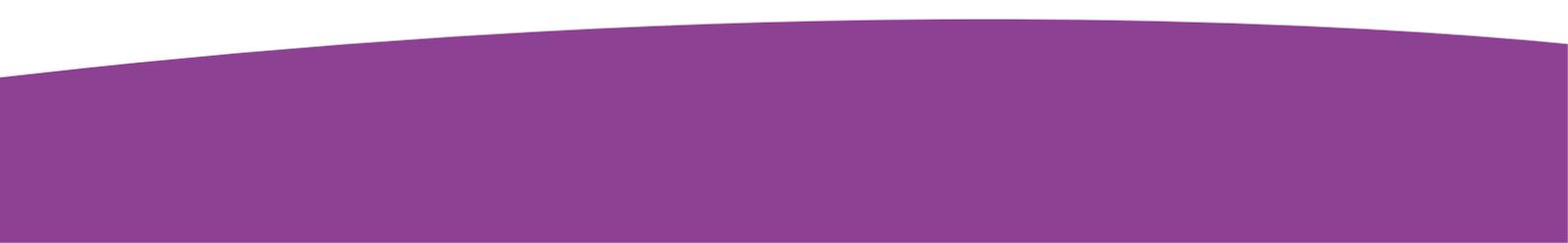
Website: http://www.do2learn.com/picturecards/printcards/selfhelp_toileting.htm

Education and resources for improving childhood continence (ERIC) – Bed Wetting or wet pant alarm.

Website: <https://www.eric.org.uk/shop/pjama-pyjama-bedwetting-pants>



Notes



Notes



Notes

As a national charity, Cerebra strives to improve the lives of children with neurological conditions through research, education and on-going family support. Living with neurological conditions can make life very hard, not just for the child but for their family too. Through the generosity of our supporters we are able to make it a little easier.

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