

# National Service Framework for Children, Young People and Maternity Services – Continence issues for a child with learning difficulties



**DH INFORMATION READER BOX**

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<b>For recipient's use</b>		

## Introduction

The *National Service Framework (NSF) for Children, Young People and Maternity Services* has been published alongside supporting material, which includes a series of exemplar patient journeys. While it is not the role of the NSF or the exemplars to provide detailed clinical discussion on individual childhood conditions, exemplars illustrate some of the key themes in the NSF.

Several factors influenced the selection of exemplar conditions, for example: large numbers of children and families affected, significant cause of illness and distress, wide variability in standards of practice or service provision and suitability for highlighting the NSF themes. Such themes include the importance of responding to the views of children and their parents, involving them in key decisions, providing early identification, diagnosis and intervention, and delivering flexible, child-centred, holistic care. Care is integrated between agencies and over time, and is sensitive to the individual's changing needs. It is also acknowledged that not every child with the same condition will follow the same journey or have the same type or severity of condition as the one which is illustrated.

The primary audience for the exemplars is professionals from a broad range of backgrounds including education, NHS, social services and the voluntary sector. They will also be of interest to parents, children and young people.

The exemplars may be useful in a number of ways; for example, to:

- highlight further references, which relate to evidence in the NSF and elsewhere, including key clinical guidelines;
- stimulate local debate and assist multi-agency partners to re-evaluate the way they collaborate on, commission and deliver children's services, for this and other conditions, to the benefit of children and their families;
- provide an aid to examining and improving local clinical and non-clinical governance;
- provide a multi-disciplinary training tool for staff working with children and young people to raise awareness of specific issues and stimulate discussion;
- canvass the views of children and families on specific children's issues (for example via focus groups), provide a non-threatening mechanism to open discussion, such as good and 'not-so-good' aspects of the current service; and
- provide a starting point or template for debate, prior to development of new local strategies for managing complex childhood conditions.

## Summary

Robert presented at 2 years 3 months as a physically healthy and happy boy, but with parental concerns about his language development. At the age of 3 years 7 months he was diagnosed with an autistic spectrum disorder. With guidance and support, by the age of just over 3 years Robert was managing to use the toilet to urinate, but it was not until he was 6 years old that he was comfortably and reliably using the toilet to defaecate without soiling accidents. During this period he had a number of bouts of constipation with overflow soiling. Robert also had a bedwetting problem, which had resolved by the age of just over 7 years.

## Key messages

- Toilet training programmes should be initiated and linked to other developmental programmes in children with special needs.
- Multi-disciplinary liaison and communication and regular ongoing support to child and parents crucial to programme success.
- Important to recognise and address persistent soiling as a symptom of underlying faecal impaction.
- Children should not be discriminated against at nursery school because they are not yet continent.
- Important to keep toilet training messages and programmes consistent between home and school, with close liaison and ongoing joint working between professionals in health and education.

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	Journey	Children's NSF theme	Evidence/links
<b>Identification of problem</b> <b>Health visitor visit 1</b> <b>Age 2 years 3 months</b>	<p>Robert was born at full term by a normal delivery. He was a healthy baby and there were no concerns about his progress at his six week and nine month checks. When Robert was 2 years and 3 months old, his mother contacted the health visitor, as she was concerned about his language development. As a result the health visitor called to observe Robert at home. He seemed a happy boy, who enjoyed playing with trains, but she felt that he was delayed in some aspects of his development, including language and other aspects of communication. He was an active little boy and was developing his motor skills, but was not yet talking and was showing minimal understanding of language in everyday contexts. He often became upset when he was in unfamiliar surroundings. As he was not showing any interest in using the potty, his mother had not yet started to toilet train him. There was a family history of learning difficulties and two of Robert's uncles had attended a special school.</p>	<p><b>Standard 1</b>  <b>Identifying needs and intervening early</b></p> <p><b>Standard 2</b>  <b>Listening to parents</b></p>	<p><i>National Service Framework (NSF) for Children, Young People and Maternity Services</i>, Department of Health (DH), 2004</p> <p><i>Healthy Child Programme</i>, 2008  <a href="http://www.dh.gov.uk">www.dh.gov.uk</a></p> <p><i>Healthy lives, brighter futures – The strategy for children and young people's health</i>, DH, Department for Children, Schools and Families (DCSF), 2009</p>
	<p>The health visitor explained that many children are not yet toilet trained at this age and suggested that Robert is encouraged to sit on the potty, but to make this a fun and stress-free experience. She gave his mother a leaflet on toilet training and arranged to visit Robert and his parents at home in two months' time. She would also request an appointment for Robert to be assessed by the speech and language therapist.</p>	<p><b>Standard 1</b>  <b>Promoting health and well-being</b></p> <p><b>Assessing needs and intervening early</b></p> <p><b>Standard 2</b>  <b>Supporting parenting</b></p>	<p>ERIC leaflet on potty and toilet training – <i>Home &amp; Dry</i>  <a href="http://www.ericshop.org.uk/leaflets.asp">www.ericshop.org.uk/leaflets.asp</a></p>
<b>Health visitor visit 2</b> <b>Age 2 years 5 months</b>	<p>The health visitor observed Robert playing at home. She noticed that he was not using any clear language and tended to throw things when he could not get attention. Robert was not at all interested in sitting on the potty, but liked putting his toy trains in it! The health visitor suggested continuing to encourage Robert to sit on the potty, and to give him a special toy to hold. It was also important to encourage Robert to have regular drinks of clear fluids, such as well-diluted squash and water. An appointment had been received from the speech and language therapy department. She also suggested that Robert might benefit from attending a playgroup to stimulate his language and play skills.</p>	<p><b>Standard 1</b>  <b>Identifying needs and Intervening early</b></p> <p><b>Standard 2</b>  <b>Supporting parenting</b></p>	<p>ERIC toilet training guidelines  <a href="http://www.eric.org.uk">www.eric.org.uk</a></p>



	Journey	Children's NSF theme	Evidence/links
<p><b>Health visitor visit 3</b>  <b>Age 2 years</b>  <b>9 months</b></p>	<p>The health visitor called to review Robert's progress. She suggested a toilet training readiness assessment to evaluate Robert's bowel and bladder maturity and his awareness of bowel and bladder function.</p> <p>She asked Robert's mother to leave his nappies off for a few days as an assessment to check how well he is able to hold his urine. She suggested that it would be helpful to use washable trainer pants for this period to be able to identify wetness and to give Robert a greater awareness of when he is dry. This would help the assessment of Robert's readiness to progress with toilet training.</p> <p>The health visitor suggested that Robert's mother continued to tell Robert that urine and faeces go in the toilet or potty. She asked his mother to sit him on the toilet or potty at regular times in his day-time routine and praise him for sitting and note if his pants are dry. She said it was best to avoid making toileting times too frequent, as it could be stressful for Robert and reduce his co-operation. She reminded Robert's mother about the importance of regular drinks throughout the day. She explained that sometimes children with delayed language also have a delay in toilet training. She gave his mother some recording charts to note his drinking pattern and times of urination as part of the assessment and this would help with planning Robert's future toileting programme.</p>	<p><b>Standard 2</b>  <b>Supporting parenting</b></p> <p><b>Standard 1</b>  <b>Identifying needs and intervening early</b></p>	<p><i>Paediatric assessment of toilet training readiness and the issuing of products</i>, Royal College of Nursing, 2006  <a href="http://www.rcn.org.uk">www.rcn.org.uk</a></p> <p>Toileting chart from <i>Paediatric assessment of toilet training readiness and the issuing of products</i>, Royal College of Nursing <a href="http://www.rcn.org.uk/search?q=toileting+chart">www.rcn.org.uk/search?q=toileting+chart</a></p>
<p><b>Speech and language therapist</b>  <b>Age 2 years</b>  <b>10 months</b></p>	<p>The speech and language therapist saw Robert and felt that he had a developmental disorder of language. She arranged for Robert to attend a weekly language group. This is a small group run by the speech and language therapist, and a nursery nurse, to encourage communication and listening skills in a fun way. The speech and language therapist said that she would liaise with the nursery that Robert would be attending and give the staff advice about his language and communication needs.</p>	<p><b>Standard 2</b>  <b>Specialist services and support</b></p> <p><b>Standard 6</b>  <b>Co-ordination of health, social care and education services to meet individual needs</b></p>	

	Journey	Children's NSF theme	Evidence/links
<p><b>Health visitor visit 4</b> <b>Age 3 years</b></p>	<p>The health visitor called to review the outcome of the toileting assessment and trial of trainer pants. This showed that Robert was able to stay dry for up to an hour, and that he sometimes showed an awareness of being wet by trying to remove his wet pants. Robert had managed some urination in the potty during the assessment. The health visitor discussed with his mother the idea of giving a small reward for Robert when he urinated in his potty. This could be an activity he enjoyed or a special toy. She suggested that Robert's mother continue the routine of taking Robert to the toilet at regular times in the day and explained that at this stage children often do not ask to go to the toilet. It was best to continue to leave nappies off to be clear to Robert that he should urinate in the toilet. She suggested including a picture cue of a toilet to be shown to him each time he was taken to the toilet to help his communication and understanding (this could be a photograph of the toilet at home). Robert was not defaecating in the potty or toilet and held his stools until his mother put a nappy on. His mother had noticed that he was defaecating less often than when he had a nappy on all the time. He was a very fussy eater – eating only white toast, yoghurt, crisps, chips and biscuits. The health visitor gave Robert's mother advice about healthy eating, and suggested that she take Robert to see the general practitioner to discuss her concerns, and ask for his opinion.</p>	<p><b>Standard 1</b> <b>Promoting health and well-being</b></p> <p><b>Standard 3</b> <b>Listening to parents, information about services and treatment</b></p>	<p><i>Every Child Matters</i>, DH, 2006 To be healthy, stay safe, enjoy and achieve</p> <p>Information leaflets from ERIC and PromoCon <a href="http://www.ericshop.org.uk/leaflets.asp">www.ericshop.org.uk/leaflets.asp</a> <a href="http://www.promocon.co.uk/publicationslist.shtml">www.promocon.co.uk/publicationslist.shtml</a></p>
<p><b>General practitioner</b> <b>Age 3 years</b> <b>1 month</b></p>	<p>The general practitioner discussed the concerns about Robert's development and his eating with his mother. He also checked that Robert had a history of a regular bowel action in infancy. He examined Robert and found that his abdomen appeared normal. He checked his spine and reflexes and looked at his bottom to check the position and appearance of his anus. He referred Robert and his parents to see a dietician to give some advice about introducing other foods and strategies to help Robert vary his diet. The general practitioner reminded Robert's mother to encourage fluids – water and non-fizzy drinks, as advised by the health visitor. The general practitioner felt his progress should be monitored and arranged to see Robert again in a few weeks.</p>	<p><b>Standard 6</b> <b>Timely access to appropriate advice and to effective services</b></p>	

	Journey	Children's NSF theme	Evidence/links
<b>Telephone contact with health visitor to review Robert's progress</b>	Robert continued to attend the language group and had regular reviews by the speech and language therapist. Robert had not defaecated in the toilet or potty. His mother reported that Robert was often soiled and did not often pass a formed stool. As this was suggestive of possible constipation, the health visitor asked Robert's mother to keep a record of his bowel habits over the next week or so. However, he had made great progress with urinating in the toilet and was now able to do this when reminded and was dry for most of the day, but did not say if he needed to urinate. Robert still wore nappies at night, as he was showing no signs of getting dry at night, consistent with many other children of his age.	<b>Standard 2</b> <b>Supporting parenting</b>	
<b>Out-patient appointment with dietician</b>	The dietician assessed Robert's diet, and gave his parents information about foods containing fibre and healthy eating. She reassured them that he is growing normally and his weight is correct for his height. She suggested that as Robert has a very restricted diet it might be good to give him a vitamin supplement daily.	<b>Standard 6</b> <b>Timely access to appropriate advice and to effective services</b>	
<b>General practitioner Age 3 years 3 months</b>	Robert's mother was concerned that Robert often had soiling episodes without any bowel awareness. She was managing his soiling by using nappies when they went out. Robert had not yet passed a stool on the toilet. His mother was concerned that his lack of bowel control would affect him when he started to attend nursery. In view of Robert's continued problems and the record his mother had kept of his bowel pattern, the general practitioner suspected constipation, and examination of his abdomen showed this to be soft but slightly distended. He prescribed polyethylene glycol plus electrolytes and asked his mother to give a half to one sachet daily. He referred Robert to the local paediatric continence clinic for further advice and support.	<b>Standard 6</b> <b>Timely access to appropriate advice and to effective services</b>	



	<b>Journey</b>	<b>Children's NSF theme</b>	<b>Evidence/links</b>
<b>Pharmacy visit</b>	Robert's mother collects the prescription for polyethylene glycol from the pharmacist. The pharmacist checks that Robert's mother understands how to take the medication, and tells her that she can dissolve the granules in any drink that Robert likes.	<b>Standard 10 Wider health promotion role of community pharmacists</b>	
<b>Nursery school Age 3 years 4 months</b>	Robert started at mainstream nursery. The nursery was uncertain how to deal with Robert's soiling and the nursery teacher suggested he came in nappies. They wanted to telephone Robert's mother to come and change him when necessary. Robert's mother contacted the health visitor who arranged to visit the nursery to discuss Robert's needs. The nursery checked the local authority guidelines on childhood continence, which clarified the need to make adequate provision to support children with continence difficulties, and suggested that meeting the needs of these children could be required under the Disability Discrimination Act 1995.	<b>Standard 8 Children with complex health needs receive co-ordinated services based on assessed needs, which promote social inclusion</b>	Disability Discrimination Act 1995 <a href="http://www.opsi.gov.uk/acts/acts1995">www.opsi.gov.uk/acts/acts1995</a>
<b>Health visitor liaison visit to nursery school</b>	The health visitor explained to nursery staff that that it was best to avoid putting Robert back in nappies, as this would give him confusing messages and she suggested they use protective pants if necessary. She also said that asking parents to be on standby to come in to change Robert might interfere with him settling at nursery, as well as causing stress for his parents. Following the advice from the health visitor, the nursery agreed to carry out a similar toilet training programme to the one his parents were using at home. The health visitor said this would be helpful, so that Robert had consistent messages from all the adults looking after him.	<b>Standard 6 Co-ordination of health, social care and education services to meet individual needs</b>	Services that are integrated – Common Assessment Framework (CAF) <a href="http://www.dcsf.gov.uk/everychildmatters/strategy">www.dcsf.gov.uk/everychildmatters/strategy</a>

	Journey	Children's NSF theme	Evidence/links
<p><b>Continence clinic community paediatrician</b>  <b>Age 3 years</b>  <b>5 months</b></p>	<p>Robert and his parents went to the specialist community continence clinic, taking with them a report from the health visitor on his toileting assessment, and his progress with the toilet training programme to date. The community paediatrician took a history and examined Robert. She found a faecal mass palpable in his lower abdomen, indicating significant constipation. Robert's anus was soiled and the skin around was reddened. She explained to Robert's parents that these findings indicated that Robert was still constipated and this would cause his soiling (constipation makes the bowel distended and this causes loss of muscle 'tone' in the bowel wall). Robert would therefore not receive signals from his bowel when it was full, and liquid stools were escaping around the hard lump of faecal matter in his rectum (lower bowel). She explained that this was a common problem in children, and many, like Robert, tend to avoid the pain of trying to defaecate by 'holding on' to their stools rather than relaxing the anal sphincter normally while sitting on the toilet. It was therefore important to combine effective treatment to help Robert's bowels to empty with continuing to develop his confidence to sit on the toilet regularly.</p>	<p><b>Standard 6</b>  <b>An integrated community-based paediatric continence service, informed by good practice in paediatric continence service, insures that accessible, high quality assessment and treatment is provided to children and their parents/carers in any setting</b></p> <p><b>Standard 8</b>  <b>Children with complex health needs receive co-ordinated high quality child and family-centred services</b></p>	<p><i>Good Practice in Paediatric Continence Services – Benchmarking in Action</i>, NHS Modernisation Agency, 2004</p> <p><i>Childhood Soiling: Minimum Standards of Practice for Treatment and Service Delivery: Benchmarking Guidelines</i>, Bonner L., Dobson P. (Ed), ERIC, 2001  <a href="http://www.ericshop.org.uk">www.ericshop.org.uk</a></p> <p><i>Promoting Continence in Children with Disabilities: Minimum standards of practice for treatment &amp; service delivery</i>, Bonner L., Dobson P. (Ed), ERIC, 2005  <a href="http://www.ericshop.org.uk">www.ericshop.org.uk</a></p> <p><i>Chronic constipation in children</i>, Rubin and Dale, BMJ, 2006; 333:1051–5</p>

	Journey	Children's NSF theme	Evidence/links
<p><b>Continen- ce clinic community paediatrician Age 3 years 5 months (continued)</b></p>	<p>The doctor explained that it would be necessary to clear out Robert's bowel by using a higher dose of polyethylene glycol and that he might need the dose increased (up to eight sachets if necessary). Robert's parents were asked to continue to record Robert's bowel pattern and details of the amount of medication that he needed. They were given written information about his medication, including a Bristol Stool Chart. Robert should also have good fluid intake in addition to the liquid used to dissolve the medication.</p> <p>The doctor told Robert's parents that once he has had a good bowel action it would be necessary for Robert to continue with maintenance dose of polyethylene glycol to prevent a recurrence of constipation and to establish a regular bowel pattern. She reassured them that it would not be harmful to continue with medication for some time – and that with successful treatment the muscle tone in the bowel would gradually recover. The laxatives could then be carefully withdrawn. The doctor introduced Robert's mother to the paediatric continence nurse, who would monitor Robert's progress and provide ongoing information and support.</p> <p>A written report with details of Robert's assessment and recommended treatment would be sent to the general practitioner, with a copy to the health visitor and Robert's parents.</p>	<p><b>Standard 10 Access to safe and effective medicines that are prescribed on the basis of the best available evidence</b></p>	<p>Macrogol preparation for children – Movicol Paediatric Plain (Norgine) <i>BNF for Children, 2009</i> <b>www.bnfc.org</b></p> <p>Bristol Stool Chart from <i>Understanding your bowels</i>, Heaton K., Family Doctor Publications <b>www.familydoctor.co.uk</b></p> <p><i>Childhood Soiling: A Guide for Parents</i>, Dobson P., ERIC, 2001, republished 2004 <b>www.ericshop.org.uk</b></p>

	Journey	Children's NSF theme	Evidence/links
<b>Paediatric continence nurse</b>	<p>The paediatric continence nurse kept in touch with Robert's mother regularly by telephone and clinic visits to monitor his progress. He needed to continue on the increased doses of the polyethylene glycol sachets mixed with juice for 4 days. She suggested that it might be best to keep Robert off nursery while his constipation was treated, so his mother could monitor the situation and give him reassurance and care. Over the next 2 days he passed very large amounts of stool in his nappies. On one occasion, Robert was able to sit on the toilet, but he was very anxious and needed a great deal of reassurance and praise. The paediatric continence nurse advised Robert's mother to continue with the polyethylene glycol and carefully reduce the amount if Robert's stools were becoming a bit loose. She should keep encouraging Robert to try short sits on the toilet after meals. She suggested that his mother uses a fun activity that involves blowing, with a whistle or party blower, as this helps to use the same muscle action as when the bowels are emptied.</p> <p>As Robert had some special needs she arranged to supply Robert's parents with night-time nappies and bed protection to help to reduce the workload and financial stress.</p>	<b>Standard 6</b> An integrated community-based paediatric continence service	Advice on bedding protection is also available from ERIC <a href="http://www.ericshop.org.uk">www.ericshop.org.uk</a>
<b>Continence clinic community paediatrician</b> <b>Age 3 years</b> <b>6 months</b>	<p>One month later, Robert was seen for review in the clinic by the community paediatrician and the community paediatric continence nurse. His mother reported that he was more lively and eating better. Robert had not yet managed to defaecate on the toilet. His mother was also worried that he was not settling well at nursery and the staff had expressed concern about his language delay and difficulty in changing activities. He was not playing with toys in the same way as other children and was not relating to his peers. The community paediatrician agreed to discuss his needs with other professionals.</p>	<b>Standard 3</b> Services co-ordinated around individual and family needs	

	Journey	Children's NSF theme	Evidence/links
<p><b>Speech and language therapist/ nursery school SENCo</b></p>	<p>The community paediatrician contacted the speech and language therapist, who agreed that there were concerns about Robert's progress in nursery with language, social and communication skills. The special educational needs co-ordinator (SENCo) at nursery agreed that Robert would benefit from a more detailed assessment. Following further discussion with his parents, the paediatrician made a referral to the local child assessment unit, to clarify his difficulties and his future educational needs.</p>	<p><b>Standard 6</b>  <b>Co-ordination of health, social care and education services to meet individual needs</b></p> <p><b>Standard 8:</b>  <b>Children with complex health needs: co-ordinated high quality child and family-centred services based on assessed needs</b></p>	<p><i>Special Educational Needs Code of Practice</i>, DCSF/581/2001  <a href="http://www.teachernet.gov.uk">www.teachernet.gov.uk</a></p>
<p><b>Paediatric continence nurse</b></p>	<p>The paediatric continence nurse kept in touch with Robert's mother and encouraged her to keep Robert on his medication for constipation. Most children need to stay on it for at least 6 months, if not longer, before gradually weaning off. She emphasised the importance of trying to make sure Robert had a good diet with plenty of fibre and lots of clear fluids. This was sometimes difficult, as Robert tended to be 'picky' with his food. The paediatric continence nurse encouraged Robert's mother to try to avoid using nappies in the day, so that Robert received consistent messages that stools go in the toilet. However, she explained that it might be necessary to put a nappy on when it looked as if he might need to defaecate – in order to prevent him holding onto his stools again. The paediatric continence nurse reassured his mother that children with language disorders were sometimes later in developing toileting skills and he would learn in time with patience and persistence.</p>	<p><b>Standard 2</b>  <b>Supporting parenting: information services and support to help care for children and ensure they are healthy</b></p>	



	Journey	Children's NSF theme	Evidence/links
<p><b>Child assessment unit</b>  <b>Age 3 years</b>  <b>7 months</b></p>	<p>Robert's parents took him for a series of visits to the child assessment unit, where his progress was evaluated by a range of professionals, including play therapists, psychologists and specialist teachers. The speech and language therapist and Robert's nursery sent reports with their observations of his skills and social development and a report from the continence clinic had also been received. At the end of the assessment, the professionals met with Robert's parents, his health visitor and nursery teacher. Robert's parents were told that the assessments showed that Robert had some learning difficulties and a difficulty with social skills, suggesting that he was on the autistic spectrum. Several members of the diagnostic team felt this diagnosis was the best way of understanding Robert's needs and providing appropriate support.</p> <p>Robert's parents were given details of the local parent support group, plus training sessions to help parents understand the diagnosis and strategies to help with the management of their child's behaviour. They were also given information about the National Autistic Society and information leaflets about autistic spectrum disorders. It was explained that the unit would advise on any benefits for which the family might be eligible and were told that Robert's progress would be followed up regularly to plan the best way to meet his future needs. The parents, health visitor, general practitioner and continence service were sent a copy of the assessment report.</p>	<p><b>Standard 6</b>  <b>Multi-agency co-operation between partners ensures timely access to appropriate services, which address their health, social, educational and emotional needs</b></p>	<p><i>The National Autism Plan for Children (NAPC)</i> produced by National Initiative for Autism: Screening and Assessment, published by the National Autistic Society, March 2003  <a href="http://www.nas.org.uk">www.nas.org.uk</a></p> <p>National Autistic Society  <a href="http://www.nas.org.uk">www.nas.org.uk</a></p> <p>Information available on:  <a href="http://www.direct.gov.uk/en/DisabledPeople/index.htm">www.direct.gov.uk/en/DisabledPeople/index.htm</a></p>

	Journey	Children's NSF theme	Evidence/links
<p><b>Paediatric continence nurse</b></p>	<p>The paediatric continence nurse kept in touch with the family throughout this difficult time and continued to encourage Robert's parents to persist with his medication and 'sitting on the toilet' regimes. She had written a simple social story to help Robert understand the need to open his bowels on the toilet. He still became very anxious about toilets, but now only needed 1–2 sachets of polyethylene glycol every day to produce a formed stool. Robert still ran behind the sofa to defaecate in his pants, and did not appear concerned about being soiled. His parents were advised to encourage him to use the bathroom by letting him help to flush the stool from his pants down the toilet and wash his hands, then praise him for doing this. He had, however, had one or two episodes of soiled pants in school. The paediatric continence nurse arranged a meeting at nursery school about Robert's toileting plan.</p>	<p><b>Standard 6</b> <b>Access to appropriate advice and effective services</b></p> <p><b>Standard 6</b> <b>Multi-agency co-operation to address health, social, educational and emotional needs</b></p>	<p>Carol Gray Social stories <a href="http://www.thegraycenter.org/social-stories">www.thegraycenter.org/social-stories</a></p>
<p><b>Meeting in nursery school</b> <b>Age 4 years</b></p>	<p>Robert's mother, nursery teacher, the speech and language therapist and the paediatric continence nurse met to review Robert's general progress and toileting programme. In view of his recent diagnosis, his teacher had made him a visual timetable with picture reminders, and had included toileting times, so Robert would know what was expected of him. The speech and language therapist had provided advice to be included on Robert's Individual Education Plan to develop his communication skills, including a picture exchange communication system (PECS) to enable him to request the toilet. The paediatric continence nurse arranged regular contact with Robert's mother to monitor his nursery school progress. Robert's mother agreed to send a change of clothes to school in case of further accidents.</p> <p>The nursery also has a programme to follow to help Robert's learning from the speech therapist and advisory teacher attached to the child assessment unit.</p>	<p><b>Standard 8</b> <b>Children with complex health needs: co-ordinated, high quality child and family-centred services which are based upon assessed needs, and which promote social inclusion</b></p> <p><b>Standard 6</b> <b>Multi-agency co-operation to address health, social, educational and emotional needs</b></p>	<p>Picture Exchange Communication System <a href="http://www.pecs.com">www.pecs.com</a></p> <p><i>Special Educational Needs Code of Practice, DCSF/581/2001</i> <a href="http://www.teachernet.gov.uk">www.teachernet.gov.uk</a></p>

	Journey	Children's NSF theme	Evidence/links
<p><b>Paediatric continence nurse</b>  <b>Age 4 years</b>  <b>3 months</b></p>	<p>At the next review appointment with the paediatric continence nurse, Robert's mother told her that Robert's bowels were opening regularly and more often in the bathroom, but not yet in the toilet. Robert was also sometimes defaecating in his nappy while sitting on the toilet. The nurse gave Robert's mother a book to help her with the next stage. She suggested that she continue to praise Robert for helping to tip the stool down the toilet, flush it away and wash his hands afterwards. The nurse suggested that Robert's mother encouraged Robert to sit on the toilet when he was defaecating in his nappy. When he was confident to do this, she could start cutting a hole in the nappy so that the stool would fall through into the toilet. If it was better for Robert, his mother could try loosening the nappy and placing it in the toilet under him so the stool wouldn't splash. They discussed giving Robert a reward for effort when he tried to use the toilet to defaecate. As Robert loved trains, they decided to get a train book to look at as a special reward (rewards should be simple, inexpensive, easily managed, and based on the interests of the individual child).</p>	<p><b>Standard 2</b>  <b>Supporting parenting</b></p> <p><b>Standard 6</b>  <b>Access to appropriate advice and effective services</b></p>	<p><i>Poo Go Home</i>, Tamsin Black, 2008                      Available from ERIC  <a href="http://www.ericshop.org.uk">www.ericshop.org.uk</a></p> <p><i>'We can do it!' Helping Children who have Learning Disabilities with Bowel and Bladder Management: A Guide for Parents</i>, White M., Rogers J., ERIC, 2002  <a href="http://www.ericshop.org.uk">www.ericshop.org.uk</a></p> <p><i>Toilet Training for Individuals with Autism &amp; Related Disorders: A Comprehensive Guide for Parents and Teachers</i>, Wheeler M., Future Horizons, 2004                      Available from ERIC  <a href="http://www.ericshop.org.uk">www.ericshop.org.uk</a></p>

	Journey	Children's NSF theme	Evidence/links
<p><b>Paediatric continence nurse</b>  <b>Age 4 years</b>  <b>6 months</b></p>	<p>Three months later Robert and his mother came back to clinic looking pleased. The paediatric continence nurse was delighted to see that Robert's diary showed that he sometimes managed to defaecate in the toilet, and he was not having many soiling accidents in his pants. He was still very anxious about using the toilet and tended to put off going, but responded to reassurance and encouragement. He was constipated occasionally, but this had improved with increasing his polyethylene glycol dosage until his bowel regularity was regained. The nurse explained that it was very important for Robert to stay on a maintenance dose of medication until he was completely confident about using the toilet and was having a regular bowel action. She told Robert's mother that it was important to avoid a recurrence of constipation, as this could make him anxious about using the toilet again. She advised that the dose of polyethylene glycol could be carefully reduced and gave his mother another copy of the Bristol Stool Chart as a guide to monitor the consistency of the stools.</p> <p>His diet had improved with gentle encouragement and he was eating more fibre. This was helping his bowel pattern. The paediatric continence nurse reminded Robert's mother to continue to encourage him to have a good fluid intake.</p>	<p><b>Standard 1</b>  <b>Promoting health and well-being</b></p> <p><b>Standard 6</b>  <b>Access to appropriate advice and effective services</b></p> <p><b>Standard 2</b>  <b>Supporting parenting: information services and support to help care for children and ensure they are healthy</b></p>	<p>Bristol Stool Chart from <i>Understanding your bowels</i>, Heaton K., Family Doctor Publications  <a href="http://www.familydoctor.co.uk">www.familydoctor.co.uk</a></p>

	Journey	Children's NSF theme	Evidence/links
<p><b>School transition meeting</b>  <b>Age 4 years</b>  <b>10 months</b></p>	<p>The nursery school arranged a transition meeting with Robert's parents and the staff at the infant school that Robert was going to attend. The paediatric continence nurse, speech and language therapist and the school nurse attached to the infant school attended the meeting. It was felt that Robert would benefit from some extra support with his language development and his toileting needs. The paediatric continence nurse agreed to write a health care plan and to give the school written advice and guidelines about the management of any soiling accidents. A copy of this was sent to his parents and to the school nurse. There was a special education teaching assistant who was willing to help with Robert's continence needs and the paediatric continence nurse arranged a meeting to discuss the care plan and answer any queries. It was agreed to keep a home school diary to record his progress and maintain communication.</p>	<p><b>Standard 6</b>  <b>Co-ordination of services to address children's health, social, educational and emotional needs</b></p>	<p><i>Every Child Matters</i>, DH, 2006                      To be healthy, stay safe, enjoy and achieve</p> <p><i>Including Me: Managing Complex Health Needs in Schools and Early Years Settings</i>, Carlin J., Council for Disabled Children &amp; DfES, 2005</p> <p><i>Improving the life chances of disabled people</i>, 2005  <a href="http://www.cabinetoffice.gov.uk">www.cabinetoffice.gov.uk</a></p> <p>Sample care plan available from ERIC  <a href="http://www.eric.org.uk">www.eric.org.uk</a></p> <p>Care plan information from PromoCon <i>Managing Bowel and Bladder Problems in Schools and Early Years Settings</i>, 2006  <a href="http://www.promocon.co.uk/managingbowelandbladderproblems.shtml">www.promocon.co.uk/managingbowelandbladderproblems.shtml</a></p>
<p><b>School nurse</b>  <b>Age 5 years</b>  <b>2 months</b></p>	<p>Robert found the change in routine with starting a new school difficult and he was very tired at the end of the day. This affected his appetite and he became constipated again. He also held onto his stools until he got home from school. He had frequent soiling accidents, mostly in the afternoons. The school nurse suggested building up Robert's confidence to use the school toilets. His teacher included a toilet reminder in his visual timetable, and this helped to remind Robert to go to the toilet after lunch. The teaching assistant helped to clean Robert if he had a soiling accident. He started to have more days when he was clean all day at school. He received a special sticker in his home school diary when he was clean to take home to show his parents.</p>	<p><b>Standard 1</b>  <b>Promoting health and well-being</b></p> <p><b>Standard 3</b>  <b>Services co-ordinated around individual and family needs</b></p>	<p>ERIC's school toilet campaign  <a href="http://www.bog-standard.org">www.bog-standard.org</a></p>



	Journey	Children's NSF theme	Evidence/links
<p><b>Paediatric continence nurse</b> <b>Age 5 years</b> <b>6 months</b></p>	<p>The paediatric continence nurse reviewed Robert's progress. His bowel pattern remained reliable with a maintenance dose of polyethylene glycol. She found that Robert was not always remembering to drink regularly at school and this seemed to be linked with a slight recurrence of his constipation. She discussed with his teacher and teaching assistant the need to encourage all the children to have a regular drink at break and at lunchtime. His parents also helped to encourage Robert to have regular drinks at home. She also suggested that if Robert had not emptied his bowels well he could have an extra sachet of polyethylene glycol at weekends.</p>	<p><b>Standard 6</b> <b>Access to appropriate advice and effective services</b></p> <p><b>Standard 2</b> <b>Supporting parenting: information services and support to help care for children and ensure they are healthy</b></p>	<p>ERIC Water is Cool in School Campaign <a href="http://www.wateriscoolinschool.org.uk">www.wateriscoolinschool.org.uk</a></p>
<p><b>School</b> <b>Age 6 years</b> <b>1 month</b></p>	<p>The school were pleased with Robert's toileting progress, as he had not had any soiling accidents for some time. Robert continued to receive additional support in school to help him with his language and social skills. His special needs were being met at School Action Plus, which meant that the SENCo wrote an Individual Education Plan to meet Robert's educational needs, with consultation with the speech and language therapist, Robert's class teacher and his parents. Every term the school staff held a meeting with Robert's parents to review and update his Individual Education Plan.</p>		<p>Education Act Special Needs 1996 <i>Special Educational Needs Code of Practice</i>, DCSF/581/2001 <a href="http://www.teachernet.gov.uk">www.teachernet.gov.uk</a></p> <p>Department for Children, Schools and Families guidance (2009) on social inclusion and pupil support, behaviour and attendance: <a href="http://www.teachernet.gov.uk/wholeschool/behaviour/">www.teachernet.gov.uk/wholeschool/behaviour/</a></p>

	Journey	Children's NSF theme	Evidence/links
<p><b>Paediatric continence nurse</b>  <b>Age 6 years</b>  <b>3 months</b></p>	<p>The paediatric continence nurse reviewed Robert's progress and was delighted to learn that Robert was now opening his bowels regularly without needing any medication, and was eating a more varied diet. She said she felt confident that his toileting would continue to be fine, providing his parents remained alert to keeping him free of constipation. He was now aware of the need to use the toilet, and was proud of his progress. The paediatric continence nurse sent him a certificate in the post with a picture of a train on it to celebrate his success.</p> <p>Robert was still wearing nappies at night. The nurse suggested that it was best at this stage to consolidate Robert's progress with bowel control and address this when he was a little older. She agreed to review his progress in six months, and gave his parents her contact details in case they needed any help in the interim.</p>	<p><b>Standard 3</b>  <b>Services co-ordinated around individual and family needs</b></p> <p><b>Standard 2</b>  <b>Supporting parenting: information services and support to help care for children and ensure they are healthy</b></p>	
<p><b>Paediatric continence nurse</b>  <b>Age 6 years</b>  <b>10 months</b></p>	<p>The paediatric nurse met Robert and his mother. Robert had had some mornings when his nappies were fairly dry. The nurse suggested that it would be good to try without night-time nappies in the school holidays when Robert was less likely to be tired. She gave Robert a book for children and a star chart to record the nights when he was dry. She reminded Robert that it was important to empty his bladder before he went to bed, and suggested a tick on his chart when he remembered to do this. She gave Robert's mother ERIC's leaflet: <i>Bedwetting: A Guide for Parents</i>. She arranged to review his progress in 6 weeks after the holidays and said that, as appropriate, there was further treatment available with a bedwetting alarm or medication. She said that bedwetting alarms usually work well, but the noise can upset younger children, especially those with learning difficulties.</p>	<p><b>Standard 2</b>  <b>Supporting parenting: information services and support to help care for children and ensure they are healthy</b></p>	<p><i>Everything a Child Needs to Know about Bedwetting</i>, Yemula C. R., Health Insights 4U, 2008. Available from ERIC <a href="http://www.ericshop.org.uk">www.ericshop.org.uk</a></p> <p><i>Bedwetting: A Guide for Parents</i>, Dobson P., 2006 <a href="http://www.ericshop.org.uk">www.ericshop.org.uk</a></p> <p>Information on Desmopressin (medication for bedwetting) available in <i>BNF for Children</i> <a href="http://www.bnfc.org">www.bnfc.org</a></p> <p>Advice on bedwetting alarms is available from ERIC <a href="http://www.ericshop.org.uk">www.ericshop.org.uk</a></p>

	Journey	Children's NSF theme	Evidence/links
<b>Paediatric continence nurse</b> <b>Age 7 years</b>	Robert visited the clinic and was very proud to show the paediatric continence nurse his star chart with several dry nights every week. She gave him a special well-done sticker and told him to say 'I can be dry' when he went to bed. As Robert was making good progress she felt that treatment for bedwetting was not needed at present. She arranged to meet Robert and his mother in two months' time.	<b>Standard 2</b> <b>Supporting parenting: information services and support to help care for children and ensure they are healthy</b>	
<b>Paediatric continence nurse</b> <b>Age 7 years</b> <b>2 months</b>	Robert and his mother came to the clinic for a review. When Robert started back at school he had some more wet nights, but since then he was usually dry at night. If he was wet it was usually linked to being tired at the end of the week. The paediatric continence nurse praised Robert and arranged to contact his mother by telephone in three months to see how he was getting on.	<b>Standard 2</b> <b>Supporting parenting: information services and support to help care for children and ensure they are healthy</b>	
<b>Paediatric continence nurse</b> <b>Age 7 years</b> <b>2 months</b>	The paediatric nurse telephoned Robert's mother and was pleased to hear that he is now mostly dry at night. He only has very occasional wet nights if unwell or worried. In view of his good progress the nurse felt confident that Robert's day and night-time bladder and bowel control was now well established. She congratulated Robert and acknowledged all the hard work his parents had put in to reach this successful conclusion. She suggested that Robert's mother could contact her should she have any queries or concerns in the future.		

This exemplar is an initiative of the children’s charity ERIC (Education and Resources for Improving Childhood Continence) and was written in conjunction with the Paediatric Continence Forum (PCF). Its purpose is to provide an example (from a child called Robert who has learning difficulties, as well as continence problems) and his ‘journey’ through NHS treatment. It puts into practice the Government’s 2004 *National Service Framework for Children, Young People and Maternity Services* and is a companion to the continence exemplar relating to Beth, a child with continence problems, which was published by the Department of Health in 2007. This exemplar is consistent with the recommendations from the Guidelines for the treatment of constipation published by the National Institute for Health and Clinical Excellence (NICE) “Constipation in children and young people: diagnosis and management of idiopathic childhood constipation in primary and secondary care May 2010” and at this stage with the Guidelines for the treatment of bedwetting, due to be published by NICE in October 2010. The exemplar was written by:

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