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*National Service Framework for Children,
Young People and Maternity Services*

Complex Disability

Every Child Matters - Change for Children

Policy	Estates
HR/Workforce	Performance
Management	IM & T
Planning	Finance
Clinical	Partnership Working

Document Purpose Best Practice Guidance

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Author DH

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Circulation list

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For recipient's use

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. Whilst 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, 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 (although they could also be of interest to parents and older children). 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 children and their families;
- > Provide an aid to examining and improving local clinical & 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.



Maria's Complex Disability

Maria has cerebral palsy. This condition often presents as a complex set of disabilities, which can vary between individuals in type and severity. In common with many young people with cerebral palsy, Maria has a mixture of physical disabilities and learning difficulties. These impact greatly on Maria and all family members, who include her parents and older siblings, Paula and Sam. In Maria's case, key problems include impaired mobility, scoliosis, learning difficulties and delayed continence. Due to the individual nature of cerebral palsy presentation, each affected child should receive a multi-disciplinary assessment and provision from health, education and social services focused around their individual needs.

		Journey
Neonatal period	v v	<ul style="list-style-type: none"> > Whilst pregnant with Maria, Maria's mother has an antepartum haemorrhage and goes into premature labour. She is treated with steroids and Maria is born at 28 weeks gestation by normal delivery. > Following immediate resuscitation and ventilation, Maria is transferred to the neonatal intensive care unit, which is at the same hospital. Here she requires continuing ventilation. > Maria's mother wants to breast feed her baby but this is not possible whilst Maria needs ventilation. She is therefore encouraged to express her breast milk to be given to Maria via a naso-gastric tube. > Specialised individual care is required, including regular physiotherapy. > During her first days, Maria develops a pneumothorax (punctured lung) and has 'jittery' movements. These require investigation to exclude infection and to assess possible causes. > The results are discussed with Maria's parents by the neonatologist, who also explains (according to good practice guidance) that these abnormal movements indicate Maria could have brain damage. He explains that Maria will be monitored carefully and provides an opportunity for them to ask questions. Staff make themselves available to answer further questions and offer parental support. > Maria's mother is discharged home after 4 days but she continues to express her breast milk which she brings to the hospital daily for Maria. The neonatal intensive care unit staff ensure that Maria's mother is put in touch with the hospital social worker, who can provide additional support to facilitate daily hospital visiting and help to arrange additional childcare that is needed for Maria's older siblings. > Maria is gradually weaned off ventilation and oxygen from about 3 weeks of age. > Following this, Maria's mother is supported by the staff to establish breast feeding.
Discharge from neonatal intensive care unit	v v	<ul style="list-style-type: none"> > At 8 weeks, Maria is being fully breast fed and discharge plans are developed in consultation with her parents. This includes the designation of an outreach neonatal nurse, who maintains links and provides support for Maria and her family after hospital discharge. > A discharge meeting is held between Maria's parents, the neonatologist and the outreach neonatal nurse. The neonatologist explains in more detail earlier investigations and provides Maria's parents with further opportunity to ask questions.

Children's NSF Theme

Evidence/Links

Standard 7 –
Timely access to specialised services.

Maria is allocated a unique NHS number at birth and her electronic NHS Care Record (NHS CRS):

www.connectingforhealth.nhs.uk/programmes/nhscrs/

Standard 11 –
Encourage mothers to breast feed.

Right from the Start template: good practice in sharing the news.

Scope & Dept of Health 2003.

- Share information sensitively and honestly.
- Provides opportunity for parents to ask question.

		Journey
Discharge from neonatal intensive care unit (cont.)	v v	<ul style="list-style-type: none"> > He explains the reasons for Maria's punctured lung and her previous breathing difficulties. He is optimistic that as Maria has been weaned off oxygen without difficulty, she is unlikely to have major chest problems. > The neonatologist shows Maria's parents her brain ultrasound scan and explains the nature of the damage which has occurred. He explains, in accordance with the Scope good practice template, that Maria is likely to have developmental problems associated with cerebral palsy. The main effect of cerebral palsy is difficulty in movement which can vary between individuals. He explains that this movement difficulty is often one of 'stiffness'. > The outreach neonatal nurse explains to the parents that liaison between the hospital and community staff will take place promptly before discharge (including physiotherapist, community paediatrician, health visitor and speech and language therapist) to ensure that Maria and her parents have all the help they need to support Maria's feeding and posture. > The neonatologist also explains that he will review Maria regularly for the first 6 months but will also liaise with the community paediatrician and community therapists at the Child Development Centre over her future assessments. > The outreach neonatal nurse provides Maria's parents with contact details for BLISS, a charity for families with premature babies. > The neonatologist writes a detailed discharge summary , which is sent within 3 days to Maria's parents, GP, health visitor and the Child Development Centre staff. > The hospital social worker also meets the family to discuss broader family issues, including caring for the other children when Maria first goes home.
Child Health Promotion Programme	v v	<ul style="list-style-type: none"> > Within one week, the health visitor visits Maria and her family at home. She introduces the subject of the Child Health Promotion Programme and its relevance for Maria over the forthcoming years. The programme is designed for all children from birth, according to national guidance. Maria's health visitor explains that her immunisations, health and developmental checks will be recorded on her electronic patient record, as well as her personal child health record.

Children's NSF Theme

Standards 3 & 8 –
Sharing information and involving parents in all stages of their child's journey.

Standard 3 –
Collaboration between different professionals and sectors providing care.

Standard 3 –
Information sharing (eg smoking cessation).

Standard 1 –
Child Health Promotion Programme.

Evidence/Links

Right from the Start template: good practice in sharing the news. 'Scope' & Dept of Health 2003.

- Share information sensitively and honestly.
- Provides opportunity for parents to ask question.

BLISS
68 South Lambeth Road, London SW8 1RL
Tel: 020 7820 9471
information@bliss.org.uk
Free helpline: 0500.618140

National Workforce Competence Framework for Children, Young People & Maternity Services (2004)
Section 4, Promotion of health & well-being.
Section 7, Care for expecting and new parents and families and their babies.
All health and social care interactions should be recorded on the NHS Care Records Service
www.connectingforhealth.nhs.uk/programmes/nhscrs/

		Journey
Neonatologist clinic 3 months	v v	<ul style="list-style-type: none"> > When Maria is 3 months of age she has her '6 week post-natal review' with the neonatologist who is pleased that breast feeding is still going well. (This review is delayed in Maria's case, due to her premature birth.) > However, over the next few months, Maria's mother becomes increasingly concerned that Maria is becoming stiff to handle. Breast feeding is becoming slow and Maria still needs three hourly feeds and tends to cry. > Maria's mother talks to the outreach neonatal nurse and health visitor about this and is encouraged to continue breast feeding. > The community physiotherapist visits Maria at home to advise on postural management. She arranges to come with Maria and her mother to the next appointment with the neonatologist. > The health professionals enter summaries of their discussions in Maria's personal child health record after each visit. They also copy Maria's parents and other professionals (including the community and hospital social workers and the GP) into all correspondence and summaries.
Neonatologist clinic 5 months	v v	<ul style="list-style-type: none"> > At 5 months of age (3 month review) Maria and her parents see the neonatologist again. Maria's parents are concerned that her weight has not progressed as well as expected and that she is becoming more stiff. > The neonatologist recommends that Maria should start weaning and liaises with the GP, outreach neonatal nurse, health visitor and Child Development Centre on this. > He examines Maria and agrees that there is stiffness on handling, which is more pronounced on the left side. > In discussion with Maria's parents and the physiotherapist who is in attendance he confirms that Maria is showing signs of cerebral palsy and that she will need a more detailed multi-disciplinary assessment. This can be undertaken at the Child Development Centre by the community paediatrician and therapists who have a special interest and experience in childhood disability. He recommends to her parents that Maria's longer term care should be handed over by him to this team. With Maria's parents agreement, a referral is made to the community paediatrician. > The outreach neonatal nurse and health visitor visit Maria again at home and provide support to her mother through observation, demonstration and advice on weaning. As feeds continue to take up to 45 minutes, she is changed to bottle feeding, which means that her father can feed her as well. At this time the outreach neonatal nurse discharges Maria from her care, but the health visitor continues to visit.

Children's NSF Theme

Evidence/Links

Standards 7 & 8 –
Listening to parents
Respect for parents
Access to specialist services

Chief Nursing Officer's review of the nursing, midwifery & health visiting contribution to vulnerable children & young people, Dept of Health 2004 – listening to children & families.

Standard 1 –
Provision of personal child health record (PCHR) for information sharing with parents and professionals.

National Workforce Competence Framework for Children, Young People and Maternity Services (2004)
Section 9, Support children, young people, parents and families during change and difficult situations.
Section 1, Communications,
Section 14, Productions and communication of information

Standard 1 –
Early identification of problems
Timely access to advice
Provision of personal child health record (PCHR).

National Workforce Competence Framework for Children, Young People and Maternity Services (2004)
Section 2, Assessment of health and well-being

Standard 8 –
Multi-agency co-ordinated services

	Journey
<p>Child Development Centre v v</p> <p>6 months</p>	<ul style="list-style-type: none"> > An appointment with the community paediatrician at the Child Development Centre is arranged when Maria is 6 months of age. > The Child Development Centre is located within an Early Support Pathfinder and Maria's family are introduced to the programme and given a copy of the Early Support Family Pack. However, the Child Development Centre is located eight miles from Maria's home. The community paediatrician tells her that Maria can have her regular reviews at the local Children's Centre instead of the Child Development Centre. The community paediatrician, who has an interest in childhood neuro-disability, runs regular sessions at the Children's Centre. > Maria's mother is pleased because Maria's siblings are already receiving some childcare at the Children's Centre. Her brother Sam attends for three mornings a week, whilst Paula, her sister, attends an after-school club three days a week. The primary school which Paula attends is co-located with the Children's Centre. > Maria's mother decides to join one of the developmental play sessions at the Children's Centre. This will enable her to meet other families who have children with a range of special needs and provide Maria with an opportunity to meet other young children. Maria's father is also encouraged to attend. > The community paediatrician explains to them according to the Scope good practice template that the investigations by the neonatal unit indicate that Maria has cerebral palsy, with stiffness which affects her left side to a greater extent than the right. She is developing head control but needs full support for sitting. This is likely to cause a delay in development of her movement skills. It is also likely to have an effect on her learning ability, although the extent is uncertain at this stage. He confirms that Maria will need future multi-disciplinary assessments. > He also confirms that screening for her vision and hearing in the neonatal period indicated that these are satisfactory. However, further assessments could be beneficial, to check for any other problems.

Children's NSF Theme

Standards 1 to 8 –
Timely access to assessment and specialist care.

Standards 3 & 8 –
Information sharing to ensure integrated assessment process.

Standard 8 –
Information to parents about child's condition and care.

Standards 3 & 8 –
Early identification, assessments & interventions, taking account of the holistic needs of the family.

Evidence/Links

Early Support is a government initiative to improve the quality, consistency and co-ordination of services for young disabled children and their families. The programme addresses many of the children's NSF themes. Further information for families can be accessed at –
www.earlysupport.org.uk

NHS Improvement Plan, Dept of Health 2004 – improve patient care closer to their home.

Scope, 6 Market Road, London N7 9PW.
Main tel: 020 7619 7100
Cerebral palsy helpline: 0808 800 3333
www.scope.org.uk

	Journey
<p>Child Development Centre √ 6 months (cont.)</p>	<ul style="list-style-type: none"> > He explains that the speech and language therapist and health visitor will continue to advise on feeding management and the health visitor will monitor Maria's weight. This can also be done at the Children's Centre, where collaboration between professionals should help to ensure an integrated service for Maria. > The paediatrician recommends that Maria should have a more detailed physiotherapy assessment, after which a joint meeting for the family, physiotherapist and himself will be arranged for feedback. > The paediatrician also explains to Maria's parents that she may have difficulties once she goes to school (special educational needs) and that it is also appropriate to give early warning to the local authority education staff, if they are content for him to do so. Maria's parents agree. > Maria's parents ask if they can be put in contact with other parents who have children with similar disabilities to Maria. The paediatrician provides Maria's parents with written information about Contact a Family, Scope and other voluntary organisations that can assist with this and offer support. > The paediatrician assures her parents that they will be fully involved in decision-making about her care at all future reviews. > Maria's parents are encouraged by the information in the Early Support Family Pack but feel they need practical help and information in managing Maria's care over the months to come. From reading the pack, they learn that a key worker is available, should they choose to request one. They decide this would be helpful and the health visitor offers to act in this capacity. She already knows the family well and she has been trained as a key worker. > The paediatrician makes a note to check for skeletal problems regularly, as he is aware that with cerebral palsy there is increased risk of scoliosis (curvature of the spine) and associated lower limb/hip deformities. Regular checks according to the protocol of Scrutton and Baird for hip subluxation (incomplete or partial dislocation of the hip joint) are also important.

Children's NSF Theme

Standard 2 –
Support and involvement of parents.

Standard 3 –
Assessment of the needs of children and their families.

Standards 2 & 3 –
Parents and families receive full information about their child's condition and treatment.

Standard 2 –
Support for parents.

Evidence/Links

Section 332, Education Act 1996 and paragraphs 4:37 & 4:38 of the Special Educational Needs Code of Practice (2001)

Contact a Family,
Tel: 020.7608.8700
Helpline: 0808 808 3555
info@cafamily.org.uk
www.cafamily.org.uk

Developing a key worker service for families with a disabled child: a resource pack (which includes the key worker standards), Care Co-ordination Network UK

Together from the Start – practical guidance for professionals working with disabled children (birth to third birthday) and their families. Dept for Education and Skills and Dept of Health 2003,
Assessment to be regarded as ongoing, not as a single event.

Scrutton D, Baird G, Surveillance measures of the hips of children with bilateral cerebral palsy. Archives of Disease in Childhood 1997; 76: 381-384 (April)
NHS CRS should record these checks:
www.connectingforhealth.nhs.uk/programmes/nhscrs/

**Child Development Centre
6 months
(cont.)** √

Journey

- > The paediatrician also makes Maria's parents aware of these risks and outlines some of the options which are available, should treatment be required.
- > The key worker will arrange appointments for assessment at appropriate stages to provide baseline information about Maria's abilities. This will help inform decisions about therapy and support. They might include a physiotherapist, who can advise on positioning and moving Maria, a speech and language therapist who can advise on feeding and early communication skills and an occupational therapist who can advise on equipment and practical aspects of daily living.
- > The key worker also makes the parents aware that home visits for some therapy sessions could be considered appropriate in the future.
- > The paediatrician explains that a written report will be provided for the parents following all these assessments.
- > To avoid Maria's parents feeling isolated prior to the next appointment, the paediatrician also provides his contact details and those of the child development team.
- > He writes to the family GP, to keep her informed of Maria's situation. A copy of the letter is sent to Maria's parents.
- > Maria's Electronic Patient Record is updated at every consultation. This will be accessible to the GP and other health professionals as required.
- > The community paediatrician also offers Maria's parents the opportunity to meet the Children's Centre social worker to discuss the family's wider needs for support.
- > An appointment is also made for the family to see their key worker to discuss the development of an Early Support Family Service Plan so that they can meet the Children's Centre social worker at the same time.
- > Another appointment with the community paediatrician at the Children's Centre is booked for one month's time using the electronic system

Children's NSF Theme

Standards 3 & 8 –
Child and family centred care to have holistic
and integrated approach.

Standard 2 –
Support for parents.

Evidence/Links

NHS Plan, the Stationery Office 2000,
chapter 10 – improved information to
empower patients.

Links to many approved information sources
via NHS Gateway: www.nhs.uk

		Journey
Children's Centre 7 months	v v	<ul style="list-style-type: none"> > Maria and her parents attend the Children's Centre one month later, as arranged. > First they see the community paediatrician. Maria's parents share their concern that Maria is developing more slowly than her older siblings and are anxious to learn how they can help her progress. The paediatrician listens and carefully examines Maria. > The paediatrician then recommends 3 monthly monitoring visits to the child development team, so that any emerging difficulties or concerns can be dealt with promptly. > Maria's key worker tells her parents about the local Portage team and explains that Portage may be helpful in supporting them to promote her development. Portage is a home-based educational support service for pre-school children, with therapists working with Portage staff to design activities for Maria's specific needs. Local authorities usually provide Portage services. Maria's parents are interested and the paediatrician explains that members of the health team can make a referral or parents can self-refer. Maria's parents decide to contact the Portage service. > Maria's key worker also explains the development of an Early Support Family Service Plan. Early Support Family Service Plans identify the range of support required by a family and how it will be reviewed. They encourage joint discussion of service needs and can prevent families being asked the same questions by different people. They do not replace other statutory assessments that need to take place. > The Children's Centre social worker joins the family and Maria's key worker for this meeting. She provides information to Maria's parents about local arrangements for childcare, benefits and support groups and how they can apply for Disability Living Allowance. She explains how the Children with Disabilities Community Social Work Team can provide support through short breaks for families with disabled children, which they may require in the future. She encourages Maria's parents to enter Maria's name on the local authority register of disabled children. This will enable them to receive regular information about local services. Maria's parents agree to this.

Children's NSF Theme

Standard 8 –
Early identification, assessment and diagnosis
of problems.

Standard 3 –
Holistic, child-centred services

Standard 8 –
Role of the key worker for children with
disabilities.

Standard 2 –
Supporting parents.

Standard 3 –
Information sharing
Integrated, holistic care
Child-centred care.

Evidence/Links

Together from the Start – practical guidance
for professionals working with disabled
children (birth to third birthday) and their
families. Dept for Education and Skills and
Dept of Health 2003
- development of a family service plan
- multi-agency co-operation

National Workforce Competence Framework
for Children, Young People and Maternity
Services (2004)
Section 15, Partnership.

National Portage Association.
www.portage.org.uk

NHS Improvement Plan - putting people at
the heart of public services. Dept of Health
2004 – ongoing assessment.

National Workforce Competence
Framework for Children, Young People and
Maternity Services (2004)
Section 3, Addressing health and well-being
needs.
Section 7, Care for expecting and new
parents and families and their babies.

		Journey
Portage Service	v v	<ul style="list-style-type: none"> > Maria's parents contact the local Portage service. A Portage adviser arranges a prompt home visit to identify how the Portage team could provide advice and support on the practical aspects of developing Maria's abilities. As key worker, the health visitor is present on the first occasion. > Maria's parents explain to the Portage adviser that Maria has had difficulty in achieving some of her milestones (for example feeding and moving) and would welcome some advice. > Maria's parents find this so useful that they request further visits. A volunteer worker from the Portage service arranges a joint visit with the therapists and, thereafter, visits on a regular basis, according to Maria's needs. The therapists continue to be available for advice and further joint visits are arranged as needed. > With the parents' agreement, the local authority educational psychologist attached to the Portage service informs the local authority of Maria's future need for assessment and support. This updates the previous information provided by the paediatrician.
Children's Centre 1 year	v v	<ul style="list-style-type: none"> > Maria's progress continues to be assessed on a 3-monthly basis by the child development team, when they hold their clinics at Maria's local Children's Centre. > Maria also continues her child health promotion programme checks and immunisations, as scheduled. These are held at Maria's GP surgery. > Although Maria is growing and developing well in some ways, her parents are concerned that she still has some marked difficulties. > Therapists' advice is incorporated into Maria's Portage programme, so that her parents are not overwhelmed with numerous clinic visits. This includes advice such as positioning, mobility, practical aspects of daily living, equipment needs, feeding and early communication skills. > Maria's therapists, paediatrician and parents are satisfied that Maria's buggy is providing good support for her back. This needs to be continually reviewed. If problems arise, a referral can be made to an NHS paediatric seating specialist clinic with input from an orthotist.



		Journey
Febrile convulsion	v	<ul style="list-style-type: none"> > Maria's parents become very concerned as Maria is off her food and has a fever with a brief convulsion lasting 2 minutes. They call Maria's GP, who visits her at home. She decides that Maria needs to be admitted to hospital and phones ahead to make the accident and emergency staff aware. Maria is then admitted to the children's ward of the local hospital overnight for observation. Maria's mother stays with her. Maria's father explains to his other children that she needs some extra care at the hospital overnight. He also leaves a message for their key worker to keep her informed. Care of Maria is focused on treatment of an acute infection, with reduction of temperature. > Maria's parents are told that the cause of Maria's convulsion is likely to have been the infection and fever. For this reason, there is no need to assume at this stage that Maria will have epilepsy in the future, though she remains at risk of febrile convulsions. Advice is given on the management of fever. > The key worker telephones the family the next day to find out how Maria is and how her parents and siblings are feeling. Maria's parents welcome the opportunity to talk through their concerns and arrange for the key worker to visit the following week.
20 months	v	
Children's Centre	v	<ul style="list-style-type: none"> > Maria and her family continue to visit the Children's Centre on a 3 monthly basis to review her progress, where the community paediatrician and other specialist consultants regularly attend. Maria's risk of deformities, particularly affecting her hips and spine is assessed. A monitoring plan is agreed. > Regular physiotherapy and occupational therapy input continues. The physiotherapist demonstrates appropriate exercises, so that Maria's parents can carry them out at home. > Information about equipment and practical support is provided by the occupational therapist, including the local equipment loan service and the Disabled Facilities Grant. > Portage continues. Maria and her mother also now attend her local Mums' and Tots' group twice a week. > Maria's parents are concerned that signs of impairment are becoming more apparent in both physical and learning aspects of development, including movement and development of speech and understanding.
2 years	v	



		Journey
Children's Centre 2 years (cont.)	∇ ∇	<ul style="list-style-type: none"> > With the agreement of Maria's parents, the Portage team together with the educational psychologist and the occupational therapist assess Maria's current perceptual and learning skills. This information provides the Portage visitor with advice about appropriate programmes for Maria. > The Children's Centre social worker recognises that the family may now benefit from additional family support. She makes a referral to the Children with Disabilities Community Social Work Team and Maria is allocated a social worker with experience of working with disabled children and their families. The social worker carries out a core assessment according to the 'Framework for the Assessment of Children in Need and their Families' to assess the needs of Maria and her family. > It is agreed that Maria's parents would welcome some regular short breaks from caring in order to spend some time with their other children. But they are worried about finding the right care. They feel Maria is too young to spend time away from the family but do not have any relatives or friends who can help. Maria's mother is concerned about the financial implications for the family and does not feel she can return to work as she had planned. > The social worker explains how direct payments can offer choice and flexibility in the arrangement of services. Maria's parents opt for a direct payment to buy some additional help for Maria at home. > Following the assessment, Maria's social worker explains that she will create a Children in Need Plan for Maria, setting out clear objectives and timescales. She explains that this will be reviewed every six months.
Convulsion 2½ years	∇ ∇	<ul style="list-style-type: none"> > Maria has another fit, lasting about 2 minutes, which is not associated with a fever. Her parents dial 999 and Maria is taken to the accident and emergency department at the local hospital by ambulance. The ambulance service phones ahead to ensure that Maria is seen quickly. Maria's mother travels with her in the ambulance. > Following emergency treatment, Maria is seen by a paediatric neurologist. After investigation, a diagnosis of epilepsy is established and she is prescribed anti-convulsant therapy.

Children’s NSF Theme

Evidence/Links

Standard 3 –
Information about condition and care
Information between family and
professionals

NHS Connecting for Health and the National Programme for IT cover both health and social care records and care plans:
www.connectingforhealth.nhs.uk/programmes/nhscrs/

Standard 2 –
Supporting parents and families.

Framework for the Assessment of Children in Need and their Families, Dept for Education and Skills and Dept of Health 2000

Standard 3 –
Addressing the holistic needs of the family.

A Parents’ Guide to Direct Payments – Dept of Health, 2003

Improving the Life Chances of Disabled People, Prime Minister’s Strategy Unit, January 2005. Chapter 5: Early years and family support

		Journey
Convulsion 2 ½ years (cont.)	v v	<ul style="list-style-type: none"> > Maria's parents suspect a familial trait, but the neurologist assures them that the epilepsy is more likely to be associated with cerebralpalsy, which carries an increased risk of convulsions. > The consultant paediatric neurologist assures Maria's parents that she will continue to monitor her progress and see her regularly. She provides them with details of national epilepsy organisations which can offer them further information. The consultant is part of the child development team and works alongside the other professionals involved in Maria's care.
Children's Centre 3 years	v v	<ul style="list-style-type: none"> > Monitoring at the Children's Centre continues on a 3 monthly basis. > Maria remains unable to walk and the physiotherapist continues to provide advice and support to maximise Maria's future mobility. Her hips are both regularly checked and x-rayed, as required. They continue to develop satisfactorily. > Maria's parents report that she is growing out of her buggy and is frustrated that she cannot get around on her own. They request provision of a suitable wheelchair. The process for this is set in motion by the child development team. With her parents' agreement, Maria is given the opportunity to trial different chairs, including an adapted tricycle. These are adapted for her individual needs by the NHS seating specialists and a suitable wheelchair is provided. > Her parents are also informed that when Maria is older, if she still has need, a charity called 'Whizz Kidz' may be able to provide her with an electric buggy that she can drive herself but which can also be remotely controlled by her parents. > Maria's parents report that Maria is not yet continent. They are told that this is not unusual for a 3 year old and that they should continue continence training and remain optimistic of improvement. Portage will be able to provide general continence advice. Occupational therapy ensures that Maria has good postural support on the toilet, so that she feels secure. Because of the family's continuing concerns, the key worker arranges a meeting with the local paediatric continence advisor. > The speech and language therapist continues to give advice on speech, language and communication skills, including alternative means of communication, such as pictures and simple signing, until Maria's speech develops.

Children’s NSF Theme

Evidence/Links

The National Society for Epilepsy
Helpline: 01494 601400
www.epilepsynse.org.uk

Epilepsy Action
Helpline: 0808 800 5050
www.epilepsy.org.uk

Standard 8 –
Ongoing assessment & monitoring.

Standards 3 & 8 –
Holistic, child-centred, integrated care.

Standard 8 –
Early identification of impairments, to
optimise positive outcomes.

Standard 8 –
Early identification of impairments, to
optimise positive outcomes.

Together from the Start – practical guidance
for professionals working with disabled
children (birth to third birthday) and their
families. Dept for Education and Skills and
Dept of Health 2003
- ongoing assessment and monitoring
process.

Whizz-Kidz, Elliot House,
10-12 Allington Street, London SW1E 5EH
Tel 020 7233 6600
www.whizz-kidz.org.uk

		Journey
Children's Centre 3 years (cont.)	∇ ∇	<ul style="list-style-type: none"> > Maria's mother reports that Maria has continuing problems in eating some food and she often chokes. The speech and language therapist advises her on the most appropriate way of feeding Maria and the occupational therapy service provides specially adapted cutlery and cups to suit her needs. > Maria continues to have intermittent convulsions and the paediatric neurologist continues regular reviews of her condition and medication. He arranges to see Maria at the Children's Centre. > Maria's parents are very anxious that she should have access to early education. Working with the Portage service, the educational psychologist and the child development team, a place at a mainstream nursery is identified where they have expertise in including disabled children and have appropriate facilities, including wheelchair access. The benefits to Maria of play with other children will promote her inclusion and assist her development in maximising her potential. > Because of Maria's complex needs, the area special educational needs co-ordinator visits the nursery prior to Maria's placement to discuss her extra support needs and to make sure that any equipment she needs is in place. She tells the staff that training is available in lifting and moving disabled children, the administration of medication and continence management through the Early Years Development and Child Care Partnership. Maria has a health plan (prepared by the child development team) which sets out her requirements for additional support.
Children's Centre 4 years	∇	<ul style="list-style-type: none"> > Maria's 3 monthly monitoring continues at the Children's Centre. > At the regular continence review, Maria's parents express concern that she remains incontinent. They receive advice from the continence advisor on how to manage Maria's toileting needs and the supplies to which she is entitled. They have a second meeting with the paediatric continence advisor and Maria's nursery to discuss further action. Maria's continence plan is reviewed. > Maria's key worker informs her parents how to apply to the Family Fund, which may be able to help them to purchase

Children’s NSF Theme

Evidence/Links

Standard 6 –
Children with incontinence have access to high quality assessment, treatment and support for the child and his/her parents.

Standard 2 –
Supporting parents.

Good Practice in Paediatric Continence Services – Benchmarking in Action 2003, NHS Modernisation Agency.
www.cgssupport.nhs.uk/PDFs/articles/Mod_Agency_Good_Practice.pdf

Family Fund; www.familyfund.org.uk
0845 130 4542

		Journey
Children's Centre	∇	<p>a new washing machine and tumble drier for Maria's extra laundry.</p> <ul style="list-style-type: none"> > They are also given the contact details of 'Education & Resource for Improving Childhood Continence', a voluntary organisation which supports the families of children with continence difficulties. > Maria remains predominantly a wheelchair user. With support from her key worker, her parents are gradually accepting that Maria is unlikely to walk very far independently and may always need a wheelchair. > Through information provided by Contact a Family, Maria's parents attend a local support group for parents of disabled children. They find it helpful to talk to parents of older disabled children and share their experiences. > During her nursery year, the educational psychologist talks with Maria's parents and, together with the nursery, they request that the local authority consider whether it is necessary to carry out a statutory multi-disciplinary assessment of Maria's special educational needs. The local authority makes use of all the assessment information collected about Maria's needs in the past 4 years. The educational psychologist provides contact details of the local Parent Partnership Service and gives the parents a copy of the parents' guide to the code. > The local authority decide it is necessary to assess Maria for her special educational needs and so carry out a statutory assessment. As part of the assessment the local authority ask for advice from her parents, the paediatrician and the other health professionals who have worked with Maria, the nursery, the educational psychologist and social services. When the assessment is completed, the local authority send the parents a draft copy of Maria's statement of special educational needs for them to consider. It sets out her needs and the kind of provision required to meet those needs. Her parents have the right to express a preference for any maintained school. After visits to local schools and some discussion with the local authority, her parents ask that a local mainstream primary school be named in Maria's statement. > Maria's parents' choice is named in her final statement of special educational needs. It is the nearest primary school and has resourced provision for children with special educational needs, particularly those with physical
4 years		
(cont.)		

Children's NSF Theme

Standard 8 –
Collaboration between partner agencies to
improve services for disabled children.

Evidence/Links

Education & Resource for Improving
Childhood Continence (ERIC),
34 Old School House,
Britannia Road,
Kingswood,
Bristol BS15 8DB
Helpline 0117 960 3060
info@eric.org.uk
www.eric.org.uk

Contact a Family,
Tel: 020 7608 8700
Helpline: 0808 808 3555
www.cafamily.org.uk

National Parent Partnership Network
8 Wakley Street,
London EC1 7QE
Tel 0207 843 6058
www.parentpartnership.org.uk

Special Educational Needs – A guide for
parents and carers
Dept for Education and Skills.

		Journey
Children's Centre 4 years (cont.)	∇	<p>difficulties and associated learning needs. It is fully accessible to wheelchair users and has support staff who are trained by health professionals. They can therefore provide appropriate support for Maria's routine healthcare needs. Visiting health professionals (for example school nurse, physiotherapist, occupational therapist, speech & language therapist and continence advisor) provide additional advice and help to school staff, as required.</p>
Maria starts primary school 5 years	∇	<ul style="list-style-type: none"> > Maria starts school along with all other rising 5 year olds. Through the statement of special educational needs Maria is provided with additional support for her learning and care needs. These are all part of the specialist resourced provision at the school. > The school nurse visits the school regularly, liaises with the paediatric continence advisor and advises the support assistant on continence issues and on any concerns about health matters such as medication and personal care. Maria needs regular toileting and changing throughout the school day. A programme to promote Maria's continence has been developed between the school nurse, the continence advisor, Maria and her parents. > The educational psychologist for the school liaises with the special educational needs co-ordinator who manages the resourced provision in the school. Appropriate strategies are put in place so that Maria can access the curriculum and make educational progress. Maria needs help with literacy and numeracy and this is provided in the main through the Primary National Strategy. The Primary National Strategy supports teachers and schools to raise standards across the whole curriculum. > Her parents are not surprised that Maria has learning disabilities, as the paediatrician had explained to them at an early stage that this might be the case. However, seeing Maria with her classmates is difficult, as it emphasises her disabilities. The educational psychologist suggests that counselling might help them and the GP makes arrangements for her parents to meet with the practice counsellor. > Maria's parents are pleased that Maria is enjoying school and making friends. The statement of special educational needs provides for co-ordination and provision of services for Maria at school. The health visitor ceases to be Maria's key worker and her social worker, who has been trained as a key worker, takes over the role.

Children’s NSF Theme

Evidence/Links

Including Me: Managing Complex Health Needs in Schools and Early years Settings (2005) Council for Disabled Children

Standard 2 –
Supporting parents.

Standard 8 –
Ongoing role of keyworker.

		Journey
<p>Maria starts primary school 5 years (cont.)</p>	<p>∨ ∨</p>	<ul style="list-style-type: none"> > At a review of Maria's Children in Need Plan with Maria's social worker, her parents explain that they find it difficult to get Maria ready for school in the morning along with her two siblings. They agree that the carer who is currently employed through a direct payment will visit earlier in the morning each day, to help Maria get ready for school. > The physiotherapist notices that although Maria has special seating, as advised by the occupational therapist and provided by the NHS, she tends to lean to the right. It is recognised that the movement of her left hip is tighter than the right. Maria is referred to the community paediatrician who orders a repeat hip x-ray. > The x-ray suggests that the hip is no longer well located in its socket. The occupational therapists discuss with Maria's parents and the school staff the importance of maintaining a symmetrical sitting position, as part of a 24 hour postural programme. > The community paediatrician arranges a prompt referral to the paediatric orthopaedic surgeon.
<p>Left hip problem – orthopaedic referral 6 years</p>	<p>∨ ∨</p>	<ul style="list-style-type: none"> > The paediatric orthopaedic surgeon meets Maria's parents and explains the problem which has arisen with Maria's left hip. He explains that although it may be necessary in the future for her to undergo hip surgery, in the meantime, it is better to watch and wait to see if the hip stabilises. Surgery would be a major step, requiring a great deal of post-operative rehabilitation. > Maria's parents agree to this plan, hoping to avoid unnecessary surgery and potential discomfort and pain for Maria. > The orthopaedic surgeon agrees to monitor Maria's progress and to liaise with other members of the child development team, as necessary. > However, by the age of 6 years, the orthopaedic surgeon confirms the hip has now 'subluxed' (become partially dislocated) and that surgery will be required. This is important, not only to correct the hip for her sitting position but also to help protect Maria's spine in the future. > Arrangements are made for surgery to be carried out at a specialist centre, where the staff are experienced in the care of children with paediatric orthopaedic conditions, including hip problems.

Children’s NSF Theme

Evidence/Links

Framework for the Assessment of Children in Need and their Families, Dept for Education and Skills and Dept of Health 2000

Standards 1 & 3 –
Timely access to appropriate specialist care.

Standard 7 –
Specialist hospital care, as appropriate.

	Journey
<p>Left hip problem – √ orthopaedic referral 6 years (cont.)</p>	<ul style="list-style-type: none"> > relief of pain and stiffness. The rehabilitation plan is written into Maria's educational goals for the year at an interim review of Maria's statement of special educational needs. > The orthopaedic surgeon continues to follow up Maria's progress until he is satisfied with her rehabilitation. He keeps other professionals fully informed.
<p>Children's Centre √ 7 years</p>	<ul style="list-style-type: none"> > Maria's epilepsy is well controlled, but she is often frustrated by her lack of co-ordination. Her speech is very limited and she is frequently distressed by her inability to communicate what she wants. Maria remains predominantly a wheelchair user. With occupational therapy supporting the family and providing advice to the school staff as to appropriate in-school programmes, there has been improvement in her fine motor co-ordination and self-care functions. > The occupational therapist, as part of the advice set out in Maria's statement of special educational needs, gives her school advice on how to help with the practical aspects of her writing skills. The programme is supported by her parents when she is at home. > Maria learns to use a switch to activate a few key words on a communication board. This requires a special programme to improve hand/eye coordination. She enjoys music and engages in all classroom activities as much as possible. > As Maria continues to grow, the school becomes increasingly worried about the management of risk entailed in lifting, moving and personal care. The school is aware of its responsibilities to develop, implement and review an accessibility plan and is progressively improving access to all parts of the school. With reference to personal care, the school arranges for staff training from the local primary care trust on lifting and moving. The occupational therapy service assess Maria and ensure that she has appropriate equipment to encourage safe moving and to maximise her participation in the life of the school. > During one of Maria's monitoring checks at 7 years, the community paediatrician notices a slight curvature of her spine. He recommends referring Maria to a spinal consultant at the tertiary centre who has paediatric expertise. Maria's parents agree to this and a prompt referral is made.



		Journey
Children's Centre 7 years (cont.)	∇	<ul style="list-style-type: none"> > The tertiary centre is an hour's drive from their home and the paediatrician says that transport to and from the clinic can be arranged for the family, if required. Maria's parents are pleased to take up the offer of transport on this occasion.
Spinal consultant referral 7 years	∇	<ul style="list-style-type: none"> > At the tertiary centre, the spinal consultant explains his role to Maria and her parents and examines Maria. He requests a full spine x-ray of Maria, which is carried out on the same day. > The x-ray confirms that Maria does have a curvature of the spine (scoliosis), despite the previous corrective hip surgery. The consultant discusses this with Maria and her parents, draws a diagram to illustrate her problem more clearly and explains the possible reasons for its development. > The consultant also explains that treatment for the scoliosis should start immediately, to support the spine as much as possible. > The consultant sets out the options. He recommends good seating and positioning as the best option at present. He also warns that the curve is likely to progress and emphasises the importance of regularly monitoring Maria's spine, through x-rays and seating reviews to reduce progression of the curve and avoid pressure sores developing. > Maria and her parents are referred by the spinal consultant to the specialist orthotics service. This service provides consultation, measurement, adaptation and provision of an appropriate wheelchair for effective spinal support. The service maintains contact with Maria's occupational therapist. > The spinal consultant updates Maria's electronic patient record and sends a letter to her community paediatrician. Copies are also sent to Maria's GP, the school nurse, therapists, special educational needs co-ordinator and her parents. > The specialist spinal nurse at the clinic provides Maria and her parents with contact details of the Scoliosis Association for additional support and advice. > Maria continues meeting the child development team at the Children's Centre close to her home and returns to the spinal consultant for a check-up after 3 months and thereafter every 6 months.

Children's NSF Theme	Evidence/Links
<p>Standards 6 & 7 – Access to high quality, timely, specialist tertiary services for diagnosis and treatment.</p> <p>Standard 2 – Supporting parents.</p> <p>Standard 8 – Information about child's condition and treatment.</p> <p>Standards 1 & 8 – Timely access to specialist care.</p> <p>Standard 3 – Information sharing.</p>	<p>NHS Improvement Plan - putting people at the heart of public services. Dept of Health 2004 – improved access to specialist care.</p> <p>Scoliosis Association UK (SAUK), 2 Ivebury Court, 323-327 Latimer Road, London W10 6RA Gen Enqs 020 8964 5343 Helpline 020 8964 1166</p>

		Journey
Paediatric spinal consultant referral 7 years (cont.)	v v	<ul style="list-style-type: none"> > Adaptations to Maria's seating are made, according to her individual needs, as she grows and develops. Advice and recommendations are provided by the NHS seating specialists, who are part of the spinal team at the tertiary spinal centre.
Personal care	v v	<ul style="list-style-type: none"> > Maria and her parents continue to need support from the continence advisor throughout her primary school years. She continues to visit Maria's school to advise the support staff on carrying out their continence care. > Maria's continence care is reviewed as she has been getting an increasing number of skin infections from using pads. She has also had recurrent kidney infections because her bladder fails to empty satisfactorily. It is agreed that an indwelling catheter could improve her quality of life. After assessment at the Children's Centre, her personal assistant at school and her parents are trained in the management of the indwelling catheter. The local primary care trust has standard protocols for invasive care and provides training to staff and families. Maria's personal assistant at school has agreed to be trained in order to give her appropriate support. > Both of Maria's siblings enjoy sport and their parents like to travel with them to school events at the weekend. But managing Maria's incontinence in transit has caused major problems and often one parent has to stay at home. The continence advisor provides contact details of an organisation which provides advocacy, information and support services for disabled people. Their services include a national key scheme, which gives access for disabled people to 4,000 accessible public toilets throughout the UK. This service enables Maria and her family to travel more easily. > Maria's family take advice about the possibility of a Disabled Facilities Grant to build a downstairs cloakroom onto their house. However, they are aware of difficulties with local planning arrangements and the space available. Their social worker suggests that they might apply to a local scheme for the installation of a stairlift which will enable Maria to sleep upstairs and use the bathroom. They obtain a grant and the stairlift is installed.

Children's NSF Theme	Evidence/Links
<p>Standards 3 & 8 – Care and treatment provided to suit individual needs.</p>	
<p>Standard 8 – Holistic, integrated care.</p> <p>Standard 3 – Information about condition and care.</p>	<p>Royal Association for Disability & Rehabilitation (RADAR), 12 City Forum, 250 City Road, London EC1V 8AF Tel 020 7250 3222 radar@radar.org.uk www.radar.org.uk</p>

		Journey
Regular reviews of special educational needs	v v	<ul style="list-style-type: none"> > Annual reviews of Maria's special educational needs continue and include Maria and her parents, the paediatrician and health therapists, school staff and Maria's social worker. As Maria continues to grow and mature, she needs continued support with personal care, including continence management. Therapy support and advice, especially physiotherapy, continue to be important. > Maria continues to have convulsions intermittently and therefore still requires additional measures at school and regular monitoring by the paediatric neurologist. > Maria is performing well below the average range in literacy and numeracy even though she has received interventions through Wave 3 of the Primary National Strategy as well as individual support. The three waves model of provision is based on systematic, graduated allocation of support, according to the needs of individual children. All those at the annual review meeting, including Maria's parents, accept that Maria's delayed learning development mean that she could be considered as a child with severe learning difficulties. Maria therefore continues to need support to access the curriculum. It is also agreed that she would benefit from the use of information technology equipment in school to help with communicating and learning. > This equipment includes appropriate interactive software, an adapted key board and the use of a touch screen.
Transfer from primary to secondary school 10 years	v v	<ul style="list-style-type: none"> > At the year 5 review of Maria's statement of special educational needs (age 10 years) planning for her secondary education is discussed with Maria and her parents. Maria has made some good friends at primary school and her hopes for secondary school are to remain with her friends and to continue to enjoy her interests such as music. Maria's parents want to ensure the best education and support for Maria. It is recommended that Maria should attend a mainstream secondary school with a special unit for pupils with physical difficulties and associated learning needs. The family agree to visit the nearest appropriate schools in order to see which one Maria and her parents would prefer. > Maria and her parents identify a local mainstream secondary school with a special unit. This is named in Maria's statement. She is pleased as she will transfer with her friends. > Maria's parents are worried about her safety in a larger secondary school. They are concerned about the risk of bullying and that her personal care may be difficult to deliver. However, the school reassures her that all children are welcome; they have an active anti-bullying policy; and the school has a team of trained learning support assistants who will ensure that Maria feels safe and does well.

Children’s NSF Theme

Evidence/Links

Standard 8 –
Treat child holistically and review needs regularly.

Chapter 3, Special Educational Needs Code of Practice (2001) and Section 4, Special Educational Needs Toolkit (2001) – Pupil Participation

Special Educational Needs and Disability Act (SENDA) 2001
- education and social inclusion of disabled child.

		Journey
Transfer from primary to secondary school 10 years (cont.)	√ √	<ul style="list-style-type: none"> > At age 11 years, Maria transfers from the primary to the secondary school. Prior to transfer, like all pupils, Maria attends her new school for taster sessions and to meet the staff. Additionally, Maria visits the secondary school with her parents to discuss her particular needs with the special educational needs co-ordinator and the head of the special unit. Following some taster sessions Maria's parents suggest that the distances which she may be required to travel between some lessons are too far. The special educational needs co-ordinator explains that Maria's time will be spent partly in mainstream classes and partly within the unit. The school makes reasonable adjustments to the year 7 timetable so that all Maria's lessons, both unit and mainstream lessons, take place on the ground floor, together with her peer group. > The occupational therapist provides additional advice to the school on relevant adaptations to the school environment, as necessary. However there is very little extra the school has to do as it is already adapted for pupils with physical and learning disabilities so that the pupils in the special unit can attend all classes as and when appropriate alongside mainstream peers. > Maria, like her brother and sister, is developing an interest in sport. The physiotherapist provides advice on how Maria can be included in physical education and games lessons. > As the school has a special unit it employs teaching assistants who are contracted to work with the pupils with learning difficulties and disabilities. Therefore Maria's statement is amended to remove the need for individual support that was required at the primary school. > A package of care has been agreed by the Primary Care Trust. A care worker who has been trained and continues to be supported by Primary Care Trust staff attends the school to provide advice, support and training to school staff on how to assist Maria with her personal care. > Maria's parents are pleased that the school has started to offer extended school services. There are a number of after-school clubs and activities including music and sport that Maria would like to attend. The school arranges for teaching assistants to support Maria at these activities as necessary.

Children’s NSF Theme

Evidence/Links

Standard 8 –
Integrated needs around the holistic needs of
the child

Standard 8 –
Partnership between professionals.

Standard 8 –
Ongoing keyworker role.

		Journey
Transfer from primary to secondary school 10 years (cont.)	∇ ∇	<ul style="list-style-type: none"> > In order to deliver Maria's statement of special educational needs the special educational needs co-ordinator arranges a meeting with therapists. This enables them to discuss how training, support and advice will be given to staff in the school on how best to support Maria and develop her independence at school. > Maria's social worker, acting as key worker, liaises with the special educational needs co-ordinator and the head of the special unit.
Spinal condition deteriorates 12 years	∇ ∇	<ul style="list-style-type: none"> > When Maria is 12 years old, it is clear that she is in the early stages of puberty and as she enters her adolescent growth spurt, her scoliosis becomes worse. As a result her next consultation with the paediatric spinal consultant is brought forward. > The spinal consultant explains to Maria and her parents, in accordance with the Scope good practice template, that Maria's scoliosis has progressed since her last x-rays. For this reason he recommends that spinal surgery should be considered for Maria. The consultant takes time to answer the family's questions and provides a detailed explanation of his recommended course of action. He explains that following spinal surgery, it is routine for the patient to be observed in an intensive care unit and/or high dependency unit. > The spinal consultant explains that due to Maria's additional risk of lower limb deformity, he would like her to be checked by a paediatric orthopaedic surgeon who specialises in this area. > Subsequent examination and investigation of Maria's legs and feet by the specialist lower limb paediatric orthopaedic surgeon, who previously operated on her hip, indicate that no further problems have arisen. > The family agree to the consultant's advice for surgery, which needs to be carried out quickly to avoid any further worsening of the scoliosis. > Maria's family are very concerned about the effect of puberty on Maria. They discuss this with the school nurse. She arranges for Maria and her mother to meet a community learning disability nurse with a particular interest in this subject who can give practical advice. The nurse also discusses with Maria and her mother how to manage her periods.

Children's NSF Theme	Evidence/Links
<p>Standard 4 – Adaptation to changing needs as young person matures and develops.</p> <p>Standard 2 – Support for parents.</p>	<p>Right from the Start template: good practice in sharing the news. Scope & Dept of Health 2003.</p>
<p>Standards 1 & 8 Timely access to specialist care.</p>	<p>NHS Improvement Plan - putting people at the heart of public services. Dept of Health 2004</p> <ul style="list-style-type: none"> - prompt and timely access for urgent treatment.
<p>Standard 3 – Working in partnership with parents</p> <p>Standard 8 – Specialist advice at the point of need.</p>	

		Journey
Preparation for the operation	∨ ∨	<ul style="list-style-type: none"> > Before spinal surgery can be carried out, comprehensive preparation is required to optimise the benefit of the surgery, whilst minimising the risk of complications. This preparation requires specialised tests and assessments from a variety of health professionals in the spinal team. They are carried out during a pre-operative visit to the hospital. > At this visit, Maria also meets her named nurse and has the opportunity to hear more about what will happen and to ask questions. > Maria and her parents are invited to contact the named nurse or the hospital pre-admission programme staff if they have further questions or concerns. Details of the hospital's Patient Advice and Liaison Service are also passed on to Maria and her family. > Provision for Maria's needs following surgery is arranged with Maria's key worker.
Spinal surgery	∨ ∨	<ul style="list-style-type: none"> > Within 3 months Maria is admitted to a children's ward at the specialist centre for surgery. Her parents are provided with hospital accommodation and there is a policy of open visiting in the children's unit, which includes siblings. > The special educational needs co-ordinator from Maria's school liaises with the local authority's home and hospital tuition service, so that Maria's education can continue on a consistent basis, when she is fit enough to participate, whilst she is an in-patient. > Maria's operation, which is called a 'combined spinal fusion', takes approximately 8 hours. > Post-operatively, Maria requires intensive care and is therefore transferred to the paediatric intensive care unit for approximately 24 hours. > The Children's Pain Management Team ensure that Maria is comfortable and able to communicate any pain problems to all staff caring for her at all stages of her stay in hospital. > The next day, Maria is transferred to the high dependency unit for a further 2 days before returning to the children's ward, where a rehabilitation regime is established to suit her individual needs. > Maria sees the specialist centre's seating experts before discharge home, to ensure that she is provided with appropriately adapted seating to support the changed post-operative shape of her spine.

Children's NSF Theme

Evidence/Links

Standard 7 –
Planned co-ordinated care package, which involves all relevant hospital departments

National Workforce Competence Framework for Children, Young People and Maternity Services (2004) for Emergency, Urgent and Scheduled Care.

Standards 3, 7 & 8 –
Child-centred services with co-ordinated assessment and care from multi-disciplinary teams.

NHS CRS facilitates information sharing involving multi-disciplinary teams
www.connectingforhealth.nhs.uk/programmes/nhscrs/

Standards 2 & 7 –
Supporting parents
Access to specialist care,
Care in child-friendly hospital environment.

NHS Improvement Plan - putting people at the heart of public services. Dept of Health 2004 –
care environment & amenities to be suitable for individual needs.
- promote effective care and optimal health outcomes

Standards 6 & 7 –
Access to specialist care, as appropriate for needs of young children, including:
24 hour cover by surgeons who are trained appropriately
Good communication skills and respect for children and families.

HBN 23 Hospital Accommodation for Children & Young People, NHS Estates 2003.

Paediatric Intensive Care: a framework for the future Dept of Health 1997.

Standards 3 & 8 –
Sharing information

		Journey
Spinal surgery (cont.)	√	<ul style="list-style-type: none"> > Maria is discharged from hospital after 10 days. She has a comprehensive discharge plan which clarifies the home nursing and personal support which will be available during her convalescent period. A discharge report is sent to Maria's parents, school and all relevant professionals.
Post-operative return to secondary school	√	<ul style="list-style-type: none"> > After one month, Maria is able to return to school. Prior to her return, the school holds an interim review of Maria's statement of special educational needs, so that staff are made aware of her post-operation rehabilitation needs and ensure appropriate inclusion and reintegration into school activities. > The paediatric spinal consultant provides post-operative follow-up reviews until Maria has made a good recovery. He then encourages and supports Maria in discussions around her future treatment and reviews. He recommends that they continue annually until she is skeletally mature. The age at which this occurs can vary between 16 and 21 years. Maria and her parents agree to this plan. > Maria's regular reviews with the child development team also continue. This provides non-surgical support in all areas of clinical need.
Growing up	√	<ul style="list-style-type: none"> > Throughout her time at school reviews of Maria's statement of special educational needs continue on an annual basis (or more frequently, as required). > Maria's social worker continues to review her Children in Need Plan every 6 months. As Maria grows up she requires less help in the mornings. With her social worker, Maria and her parents discuss the priorities in Maria's life at that time. They agree that Maria would benefit from participating in more leisure and sporting activities with her friends and that their direct payment can be used to employ a personal assistant to accompany Maria to activities when necessary. > Regular reviews also continue with the child development team at the Children's Centre.



Children's NSF Theme	Evidence/Links
<p>Standard 8 Co-operation between health and education services to ensure appropriate information sharing and that individual needs of the child are met.</p>	<p>Access to Education for Children and Young People with Medical Needs. Dept for Education & Skills and Dept of Health, 2001.</p>

		Journey
Planning for transition to adult life 13 years	∨ ∨	<ul style="list-style-type: none"> > At year 9 (age 13 years) as part of the annual review process Maria's school organises a meeting to draw up a transition plan. Relevant professionals from health, social services and the youth services are invited, together with an advocate from the local voluntary sector scheme to support Maria in communicating at the meeting. > The meeting follows a person centred approach. This will support and actively involve both Maria and her family in the transition planning process. > At the meeting Maria's statement of special educational needs is discussed and the plans for her education in years 10 and 11 are agreed. In addition, with the support of her advocate, Maria explains her ideas for her life once she is adult. > Working with the school and other agencies, the youth support service draws up a Transition Plan following the review meeting and Maria's advocate ensures the information is given to her in an accessible format. > The Transition Plan sets out a number of objectives including: <ul style="list-style-type: none"> > Curriculum objectives for Maria's remaining years at school > A review of her epilepsy > Assessment of options for continuing education in the further education sector at 16 years of age. > Agreement on arrangements for Maria's transfer from paediatric to adult rehabilitation services > Advice for the family on housing options for the future. > The Transition Plan will be reviewed annually or more frequently as required. > The community nurse suggests that in the future, Maria and her parents may wish to consider participating in the Expert Patient Programme as an aid to managing her long-term disabilities. She provides details of the web address for the family to obtain further information. > Maria and her family are reminded that they can apply for a Disabled Facilities Grant. Although they have a stairlift installed, they feel that Maria's age and increased weight now necessitate adaptations to the bathroom and other parts of the family house. They apply for a Disabled Facilities Grant which pays for the required adaptations to the home.

Children's NSF Theme

Standard 4 –
Growing-up. Transition processes are planned and focused around the young person.

Standards 3 & 8 –
Ongoing assessment and review to reflect changing needs.

Evidence/Links

Special Educational Needs Code of Practice ch 9 annual review, and transition plan, Dept for Education and Skills, 2001

National Workforce Competence Framework for Children, Young People and Maternity Services (2004)
Section 6, Work with children, young people, parents and families to enable them to improve their health and well-being.

Valuing People - A New Strategy for Learning Disability for the 21st Century, Cm5086, The Stationery Office, March 2001

Expert Patient Programme –
Tel 0845 606 6040
www.expertpatients.nhs.uk

Delivering Housing Adaptations for Disabled People: A Good Practice Guide, November 2004, Office of the Deputy Prime Minister, Dept of Health and Dept for Education and Skills.

		Journey
Planning for transition to adult life 16 years (cont.)	v v	<ul style="list-style-type: none"> > The social worker reviews Maria's and the family's benefits and allowances. Their eligibility may have changed since Maria was younger and they may be missing out on some entitlements. The social worker agrees to assist the family in making the necessary applications. When Maria is approaching her 16th birthday, the social worker explains to Maria and her family that she can have direct payments in her own right from 16 years of age. > Maria's family ask for a carers' assessment – they are concerned about the future and their ability to continue caring for Maria at home without some additional support. > In years 10 & 11 (age 15-16 years) of Maria's school career, the youth support service works with the local children's trust's multi-agency transition team to put in place support and a person centred plan, which she will need after leaving school. > The youth support service liaises with the local further education providers about appropriate courses for Maria. They assess her needs for support at the further education college. They assist Maria in making her application and provide a link with a further education college to ensure that Maria's need for extra support is met. Funding is available through the Learning & Skills Council to make provision for Maria's special needs. With Maria's agreement, her transition plan is transferred to the Learning & Skills Council and the selected further education college, prior to her entry. > The youth support service also explains to Maria that they can support and advise her until she is 25 years, if she wishes. Maria's family are reassured by this.

Children's NSF Theme

Evidence/Links

Standard 2 –
Support for parents

Standards 3 & 8 –
Holistic, integrated approach to care, around
the needs of the young person.

Standard 8 –
Inclusion for young people with disabilities

Direct Payments Guidance, Community
Care, Services for Carers and Children's
Services (Direct Payments) Guidance
2003. Dept of Health.

My Money, My Way – A Young Person's
Guide to Direct Payments, Scope, 2004

Carers and Disabled Children Act 2000 and
Carers (Equal Opportunities) Act 2004
Combined Policy Guidance, Dept of Health
2005

Learning & Skills Act 2000
Section 140 – assessment

		Journey
<p>Transition to adult services 19 years</p>	<p>∨ ∨</p>	<ul style="list-style-type: none"> > Maria makes some increases in confidence and independence. Her parents begin to explore options for the future, but emphasise the importance of education and support continuing until she is at least 25 years old. > Arrangements are made for Maria's transfer from paediatric to adult rehabilitation services. > At age 19 years, when Maria attends her annual spinal review, the spinal specialist explains, following further x-rays, that she has reached skeletal maturity. This means that since she has stopped growing, her skeleton should now be more stable. It will not be necessary to continue with her annual spinal reviews. However, he advises that as he has responsibility for adult patients too, if Maria needs further orthopaedic advice he would be pleased to see her again. He checks carefully that Maria has understood his advice. Maria and her family confirm that they are happy with this arrangement. > The spinal specialist sends a final report to Maria's community paediatrician and GP, explaining his discussion with Maria and that he has discharged her from further paediatric spinal reviews. > At Maria's next child development clinic, the community paediatrician says that he has heard from the paediatric spinal specialist. He discusses with Maria and her family the question of transferring her future clinical reviews to the local adult disability service. The team includes health professionals who have expertise in supporting young adults with cerebral palsy and learning disabilities. > Maria is assured that the transfer of care would be a gradual process, so that she is familiar with the new team (and they with her) before they take over full responsibility for her reviews. Maria and her family have a few questions but agree to give the new arrangements a try. > Once Maria has had an opportunity to meet members of the paediatric and adult teams jointly and is reassured that the transition will be smooth she is pleased to have her reviews formally transferred and included in her health action plan.

Children's NSF Theme

Evidence/Links

Standard 4 –
Growing up into adulthood, smooth
transition to adult services.

Improving the Life Chances of Disabled People, Prime Minister's Strategy Unit, January 2005. Chapter 6: Transition to adulthood.

National Service Framework for Long-term conditions, Dept of Health, March 2005;
Quality requirement 5 –
community rehabilitation & support to meet individual changing needs.
Quality requirement 4 –
access and re-access.

NHS CRS ensures a smooth transition from children's services to adult services.
www.connectingforhealth.nhs.uk/programmes/nhscrs/

Valuing People - A New Strategy for Learning Disability for the 21st Century, Cm5086, The Stationery Office, March 2001





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