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Acquired Brain Injury

Change for Children - Every Child Matters

Policy	Estates	
HR/Workforce	Performance	
Management	IM & T	
Planning	Finance	
Clinical	Partnership Working	
Document Purpose	Best Practice Guidance	
ROCR ref:	Gateway ref: 4284	
Title	Acquired Brain Injury, National Service Framework for Children, Young People and Maternity Services	
Author	DH	
Publication date	15 Dec 2004	
Target audience	PCT CEs, NHS Trusts CEs, SHA CEs, PCT PEC Chairs, Special HA CEs, GPs, SHA Children's Leads, NHS Trusts Children's Leads, A&E Departments, Ambulance Trusts, Children's Hospices CEs, Local Authorities, Other Government Departments, Copies to NHS Foundation Trust for information	
Circulation list		
Description	This is the exemplar on Acquired Brain Injury which forms part of the National Service Framework for Children, Young People and Maternity Services.	
Cross ref	Children's NSF	
Superseded docs	N/A	
Action required	N/A	
Timing	N/A	
Contact details	Claire Phillips, Children's NSF Team, 526 Wellington House 133-155 Waterloo Road, London SE1 8UG.	

Introduction

The National Service Framework (NSF) for Children and Maternity Services will be 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 or aspects of pregnancy or childbirth, 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, which 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 (eg 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.

Jack's Acquired Brain Injury (ABI)

Jack, aged 8 years, was escorted to school everyday by his mother. Usually they crossed the road via the zebra crossing close to the school gates.

One morning before they reached the gates, Jack wanted to cross the road to see a friend who was on the other side. Unfortunately, he did not have a clear view of the road, due to the parked cars. When he stepped into the road, a passing van, which was going too fast, was unable to stop in time. Jack was thrown some distance, hitting his head and sustaining multiple injuries.

		Journey	Children's NSF Theme
Seeking Treatment	¥	> The emergency ambulance is called by onlookers and arrives promptly within 5 minutes. Jack remains conscious. He is assessed and initial management instituted (airway optimised, breathing assessed, oxygen given, circulation assessed and spinally immobilised on scene). To minimise pre-hospital time, Jack is given pain relief and IV cannulation in the ambulance, during transfer to the nearest A&E Department. His mother is able to accompany Jack in the ambulance.	Standard 1 & 3 – timely access to treatment
Accident & Emergency Department (A&E)	¥	> Jack is taken to the Children's Unit at the A&E Department of the district general hospital, which is run by paediatric trained staff. Following initial triage and investigation by an A&E consultant and advice from an orthopaedic surgeon, Jack's physical injuries are diagnosed as bruising to the side of his head, fracture of left forearm, with soft tissue injuries to the face and hands. Jack is treated in A&E Department as appropriate for these injuries [eg plaster of Paris (POP), sutures]. In view of the head injury, he is to stay in hospital overnight to monitor for possible intracranial injury. A paediatrician is called to see Jack before admission to the children's ward.	Standard 1 & 3 – timely access to treatment Standard 6 & 7 – care in a child-friendly environment

Evidence/Links

Ambulance response times – category A – 75% response time within 8 mins

Head Injury; Triage, assessment, investigation & early management of head injury in infants, children & adults, National Institute for Clinical Excellence, June 2003 – pre-hospital management.

Joint Royal Colleges Ambulance Liaison Committee (JRCALC) clinical practice guidelines; section 6, paediatric trauma emergencies, 2004

National Standards, Local Action; Health & Social Care Standards & Planning Framework 2005-2008, Dept of Health 2004 Appendix 1: existing commitment – maximum 4 hr wait in A&E from arrival to admission/transfer/discharge.

	Journey	Children's NSF Theme
Accident & V Emergency Department (A&E)	> Jack's father at the hospital by car, when he hears of his son's accident. The doctors keep Jack's parents informed of his condition. They are also offered support and practical assistance by the nursing staff.	Standard 2 – supporting parents
(cont.)	> Just before transfer to the paediatric ward, the nurses raise concern about Jack's neurological observations because his pupils have become unequal size. Jack's condition suddenly deteriorates, he starts to 'fit', stops breathing and requires resuscitation, intubation and ventilation. The paediatrician calls the paediatric intensive care consultant, who is asked to re-assess Jack. They then call the specialist paediatric intensive care unit (PICU) at the neurosurgery centre 30 miles away and agree that urgent transfer to PICU is necessary. The paediatric intensive care consultant also recommends other immediate treatments because of the urgency of the situation (a probable extradural haemorrhage.) Jack is taken by emergency ambulance with life-support facilities and is accompanied by a consultant anaesthetist, rather than waiting for the retrieval team.	Standard 6 & 7 – access to appropriate care and staff trained in the care of children
	> A&E staff check Jack's parents' arrangements for travelling to the tertiary centre and are assured that friends will give them a lift and take care of their other children.	Standard 2 – supporting parents
Paediatric Intensive Care Unit (PICU)	 > The PICU consultant discusses Jack's referral with the paediatric neurosurgeon at the specialist centre before his arrival. > At the tertiary centre Jack has a head CT scan and requires immediate surgery for an extradural haemorrhage. He remains unconscious for about one week and requires intensive life support. 	Standard 6 & 7 – specialist care available, as appropriate to the needs of young children
	 > A room is provided in the hospital, close to PICU, to enable his parents to be resident. Jack's parents have arranged for Jack's siblings to stay with relatives and visit hospital each day. > The paediatric neurosurgeon and PICU consultant discuss Jack's progress with his parents on a regular basis. They are made aware of the risks due to Jack's brain injury, and the uncertainty of outcome at this stage. They assure his parents that Jack's GP will be 'put in the picture' straight away and be 	Standard 2 – supporting and empowering parents to care for their children

Improving the Patient Experience Dept of Health 2003 – *Appendix 1, Children cared for in an environment equipped for their needs and by staff trained to meet those needs.*

National Service Framework for Long-term conditions, Dept of Health 2004, Quality Requirement 3 - emergency & acute management.

National Standards, Local Action; Health & Social Care Standards & Planning Framework 2005-2008, Dept of Health 2004. Appendix 1: existing commitment – delayed transfer of care to be reduced to a minimal level by 2006

Improving the Patient Experience, Dept of Health 2003 – Appendix 1, accommodation should be offered to parents of children in hospital and they should be encouraged to stay

Headway, Brain Injury Assoc. 4 King Edward Crt Nottingham NG1 1EW Tel: 0115.924.0800 www.headway.og.uk

		Journey	Children's NSF Theme
Paediatric v Intensive Care Unit (PICU) (cont.)	v	> Jack's 'named nurse' provides a focus for co-ordination of Jack's care in PICU. The nurses offer comfort and support to the family. In response to Jack's father's concerns about his job, the nurse suggests that he visits his GP to obtain a sick note. This will enable him to have leave from work to be with Jack in hospital.	Standard 3 – information for parents and caring for children in the context of their family
		> Jack's parents are provided with written material about his condition and care, including information on relevant voluntary organisations and parent support groups. With their agreement, a link is made with a local voluntary organisation co-ordinator by the 'named nurse'.	
		> Early intervention to accelerate Jack's rehabilitation is part of routine care. This includes assessment and input from a physiotherapist (eg chest) and speech therapist (eg swallowing reflex) and occupational therapist (eg identifying appropriate levels of sensory stimuli).	Standard 6, 7 & 8 – early intervention to aid recovery and rehabilitation
		> The hospital social worker visits Jack's parents and offers her practical support and assistance, promises to stay in touch and provides her contact details. She ensures that the parents have information on financial support for hospital visiting and for any childcare associated with visiting Jack.	Standard 3 – co-ordinated and holistic care for the child and his family
		> The hospital chaplain visits Jack and his family to provide pastoral care and offers his future support.	Standard 3 – respect for children's and family's individuality and beliefs
		> Early support of parents in PICU is also provided by the paediatric clinical neuropsychologist.	
		> Prior to leaving PICU, members of the rehabilitation team who will be involved in Jack's care when he is transferred to the paediatric ward come to meet the family. Their aim is to ensure a smooth transition and allay family anxieties about the process of transfer to a new environment and regime of care.	

Child Brain Injury Trust, The Radcliffe Infirmary, Woodstock Road Oxford, OX2 6HE Tel: 08456014939 www.cbituk.org/

British Institute for Brain Injured Children Knowle Hall, Knowle, Bridgwater, Somerset TA7 8PJ Tel: 01278 684 060 Web: www.bibic.org.uk

Contact-a-family Tel: 020 7608 8700 Helpline: 0808 808 3555 Email: info@cafamily.org.uk

Emerging Findings, Dept of Health 2003, Ch 5, *Disabled children and long-term conditions. Family-centred services that address all types of need.*

National Service Framework for Long-term conditions, Dept of Health 2004, Quality Requirement 4, early and specialist rehabilitation

	Journey	Children's NSF Theme
Transfer to v Paediatric Ward	> When Jack has been weaned off life support and no longer needs intensive care, he is transferred from PICU to the high dependency unit for a short interim period before moving on to a paediatric ward at the same tertiary centre.	Standard 7 – hospital standard. Access to appropriate specialist care.
	> Here, his clinical and rehabilitation care is led by a paediatric neurologist, with a multi-disciplinary team of therapists who specialise in neurorehabilitation.	Standard 8 – early intervention to prevent irretrievable loss of function and ability
	 Jack still has POP to his left arm but the injuries to his hands and face have healed and the sutures have been removed. It is important not to delay the next stage in his rehabilitation, in order to ensure that the recovery of his abilities is maximised. 	
Functional Ability V Assessments	> A range of clinical assessments by the rehabilitation team is arranged to provide an overall picture of Jack's functional ability, to include:	
	occupational therapy, physiotherapy, audiology, optometry/orthoptist, speech & language therapy, paediatric clinical neuropsychology, hospital teaching service, play therapy, dietetics.	
	> The assessment results show that Jack has sustained brain damage, which has affected:- co-ordination; fine movements; self-care skills; mobility & balance; hearing in left ear; vision (squint); speech (dysphasia); short term memory & attention; executive skills; behaviour.	Standard 8 – comprehensive disability assessment.
	> With Jack's parents' agreement, relevant information about the assessment results is communicated to health, social and education colleagues in all sectors, which are (or anticipated to be) involved in his care.	Standard 1 – early intervention.

House of Commons Select Committee on Health report Head Injury Rehabilitation 2001 – rehabilitation to start as soon as possible after medical stabilisation

House of Commons Select Committee on Health report Head Injury Rehabilitation 2001 – people with suspected brain injury assessed by specialist staff and nursed in an appropriate location to their needs.

Framework for the assessment of children in need and their families, DH & DfES, 2000 www.dh.gov.uk

	Journey	Children's NSF Theme
Case Review – V Family Explanation & Discussion	> The results of Jack's assessments are the subject of a case review, attended by the multi-disciplinary/ multi-agency ABI rehabilitation team. Jack and his parents attend, although Jack can stay only so long as his tolerance/stamina allows at this stage.	Standard 3 – information sharing and involving family in decisions.
	> At the case review, representatives from the rehabilitation team led by the paediatric neurologist answer the family's queries on the assessment results. They explain, in accordance with the 'Scope' good practice template, that the results indicate that Jack has some degree of acquired brain injury (ABI). They also explain that -	Standard 8 – co-operation between professionals, sharing information.
	> ABI is a disability for which symptoms will vary according to the site and severity of the injury to the brain. As ABI, in many cases, cannot be seen it is often known as a 'hidden disability' and can also have other causes, e.g. meningitis, encephalitis or after brain tumour and its powerful life-saving treatments.	Standard 8 – keeping parents fully informed and involved at each stage.
	> Jack's excessive fatigue is a typical symptom post-ABI.	
	> Although it is too early to say precisely what the long-term outcomes of Jack's ABI will be, there is good reason to expect significant improvement. A full rehabilitation programme, tailored to suit Jack's individual needs, will speed his progress. This will include all aspects of his well-being; involving health, social and educational input.	
	> There are no long-term effects from Jack's other physical injuries.	
	> Jack and his family are reminded of relevant contact details and also offered non-clinical support through,	Standard 2 – supporting parents.
	 the hospital paediatric social worker who, with the family's agreement, is named as Jack's key worker, 	Standard 3 – holistic care in context of the whole family.
	- local support groups (reminder of contact details)	Standard 8 –
	 counsellor/mentor/advisor - support for emotional and bereavement needs (through local support group or neuropsychology service). 	disabled child to be given key worker.

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

National Standards, Local Action; Health & Social Care Standards & Planning Framework 2005-2008, Dept of Health 2004. Priority II - supporting people with long-term conditions; personalised care plans for vulnerable people most at risk. Fourth domain - patient focus, core standard

13; patients, relatives and carers treated with dignity and respect.

	Journey	Children's NSF Theme
Rehabilitation ^V Programme	> The rehabilitation team, led by the paediatric neurologist, with Jack and his parents, develop his rehabilitation programme, tailored flexibly to his individual needs, which includes a range of identified functional goals. It also starts to address discharge planning by looking forward to Jack's anticipated needs, once he returns to his home environment	Standard 3 & 8 – Timely access to treatment, Co-ordinate care, Child-centred approach, Family/holistic context
	> The family is informed that Jack can go home once good progress is established.	
	> Jack remains in the paediatric ward for a further 6 weeks for monitoring and rehabilitation. For the sake of continuity, he and his family preferred to stay in the same ward, rather than take the option of being transferred to the family's local hospital.	
	> Once discharged, his rehabilitation can continue with input from the local paediatric clinical network and other services local to Jack's home.	
	> Jack responds well to his physical rehabilitation but he still needs assistance with self-care, mobility and speech difficulties. Persisting fatigue requires his rehabilitation to include graded activity programmes and time to rest.	
	> However, Jack's parents notice uncharacteristic changes in his behaviour and moods. He now becomes easily angered and upset and is unable to concentrate. Staff report that he has sudden mood swings when he may refuse to co-operate.	
	> The paediatric clinical neuropsychologist receives feedback on Jack's behavioural changes and develops, with Jack, his family and the staff some coping strategies.	Standard 9 – psychological needs of children with health problems
	> The orthoptist reports that Jack's squint has gradually resolved, although follow-up to check that improvement has been maintained is recommended.	Standard 3 – caring for the needs of the whole family
	> Repeat audiology tests show that Jack still has left-sided hearing loss.	Standard 2 – supporting parents
	> The play therapist observes Jack and finds stimulating games for him to play.	

'High & Dry', Child Brain Injury Trust, 2003 – need for improved post-acute rehabilitation in the hospital setting.

National Standards, Local Action; Health & Social Care Standards & Planning Framework 2005-2008, Dept of Health 2004. Priority II - supporting people with long-term conditions

House of Commons Select Committee on Health Report, Head Injury Rehabilitation 2001 – Acute trusts to ensure that rehabilitation starts as soon as possible after medical stabilisation, with specialist rehabilitation unit and staff

Access to Education for children and young people with Medical needs. DfES, DH 2001

	Journey	Children's NSF Theme
Rehabilitation V Programme (cont.)	> Jack attends the hospital school daily for short periods. Therapists liaise with the teacher to advise on the learning impacts of his disability and how to choose and adapt activities, which will reinforce his rehabilitation. Strategies to improve his speech are recommended by the speech and language therapist. Equipment such as adapted seating, a computer key guard and special pencil grip is provided by the occupational therapist. The hospital school teacher provides stimulating activity and helps him to regain earlier reading and writing skills.	Standard 8 – inclusion of disabled child
	> Jack's school and the Local Education Authority (LEA) are kept informed of Jack's condition by the hospital teaching service/paediatric clinical neuropsychologist.	
	> The hospital social worker, as key worker, also provides support for the family's wider needs. These include cost of transport to/from the hospital, advice on child care for Jack's siblings, benefits entitlement and, together with the occupational therapist, housing problems arising from Jack's new circumstances.	
	> With agreement from the parents, the hospital social worker contacts social services in Jack's home authority to give forward notice of his discharge, so that it can be planned appropriately, with any practical support in advance (eg loans of equipment).	Standard 3 – information sharing.
Hospital Discharge V Care Plan	 > After about 10 weeks, it is explained to Jack and his parents that, with their agreement, he is now improved enough to go home. > A discharge plan for his return home is developed and agreed by all parties, including Jack, his parents, clinical, social services and LEA. It is then agreed that the social worker in Jack's home area will take over as his key worker. 	Standard 7 – Hospital standard – Co-ordination of care between hospital, community and social services; Individual discharge plan.

Disability Discrimination Act 1995 – inclusion of disabled people.

National Standards, Local Action; Health & Social Care Standards & Planning Framework 2005-2008, Dept of Health 2004. Priority II - supporting people with long-term conditions; comprehensive, holistic assessment of current and anticipated health and social care needs and wishes.

	Journey	Children's NSF Theme
Hospital Discharge ↓ Care Plan (cont.)	 > The plan includes; Arrangements to enable Jack to go home for short stays in the first instance, graduating to longer periods. This will allow for slow integration at home, to help the whole family prepare for Jack's long term difficulties. This will also enable the family to ask for advice, based on the actual experience of Jack returning to his home environment (rather than speculation), prior to his final discharge. Discharge information/letters from the rehabilitation team to the GP, primary care, community teams, LEA, special educational needs co-ordinator (SENCO) and social services informing them of Jack's condition and need for support. The paediatric neurologist backs up his correspondence with a phone call to Jack's GP, to provide an opportunity for queries and further discussion about what input Jack will need from primary care. He also alerts the LEA to the fact that Jack has ABI and, as such, a 'watching brief' should be maintained throughout his schooling, as difficulties can emerge later, even when Jack appears to have recovered. He recommends immediate multi-disciplinary assessment (MDA) for a statement of special educational needs. The various completed hospital reports can be made available for the LEA MDA process. Pending this, home teaching would be required with later gradual re-introduction to mainstream school, as/when agreed between the family and professionals. Arrangements to be put in place for continuation of rehabilitation with the community therapists. OT to organise loan of wheelchair and commode from local equipment facility, Physiotherapy and OT visit Jack's home to assess mobility and self-care needs during one of his short home stays - but prior to his discharge from hospital. As Jack's family live in a local authority (LA) house, the OT requests the installation of a second toilet on the ground floor, a handrail to provide support and a wheelchair ramp. Advice on adaptations, equipment and posture is al	Standard 9 – psychological needs of children with physical conditions. Standard 3 and 8 – liaison between agencies about children who have complex needs (eg) - education, - primary care, - community, - social services Standard 3 & 8 - holistic care of the child and family.

House of Commons Select Committee on Health Report, Head Injury Rehabilitation 2001 – recommendation (vii) acute sector to take responsibility for planning onward care journey.

Access to Education for children and young people with Medical needs. DfES, DH 2001

Special Educational Needs Disability Act (SENDA) 2002 - flexible education provision to facilitate access.

NHS Improvement Plan, Dept of Health 2004, Ch 7 – improved information sharing for the benefit of patients.

House of Commons Select Committee on Health Report, Head Injury Rehabilitation 2001 – co-ordination of services in the community.

Supporting people with long-term conditions, Dept of Health 2004 - support to stay in own home.

National Standards, Local Action; Health & Social Care Standards & Planning Framework 2005-2008, Dept of Health 2004 - existing commitment, hospital appointments will be booked for convenience of patients.

	Journey	Children's NSF Theme
Return Home V	 > Jack is taken home by his parents in the family car. > He takes the wheelchair with him, which the hospital OT has obtained on loan. > Jack's parents organise a sofa in the sitting room to provide him with a day bed, as required, and to facilitate more family inclusion. 	Standard 3 and 8 – Child-centred care in family context.
Rehabilitation and follow-up care	 In accordance with the hospital's discharge plan, Jack's GP, primary care, community, social services and education teams all receive the necessary information about Jack. This is planned to arrive at least one week before Jack's discharge, so that smooth hand-over can be organised, including delivery of equipment. The local children's social worker visits the family and offers ongoing practical support. As Jack's key worker, she carries out an assessment of his and the family's wider needs. The GP, who has received a full summary of Jack's hospital course, pays a home visit to assure himself that there are no outstanding concerns, which need his immediate action The community matron (or school nurse) links with the key worker (social worker) and in addition provides a link between the family and the local health services. She assures Jack's family that she will keep the school up-to-date with his progress, ready for his later return to school. The community physiotherapist visits and shows Jack and his parents how to manage the stairs safely and the exercises he can do to improve his balance. The community OT also calls and checks how Jack is managing with self-care and the adapted equipment -and advises, as appropriate. She shows him activities to improve his functions and helps his siblings and friends to understand his needs to join in play. LEA put in place an individual education plan for Jack, with immediate effect, which includes a home teacher. Thus Jack continues his rehabilitation at home with input from his family, the primary care team, community therapists, school nursing service, LEA and supported by the neuro- and educational psychologists. 	Standard 3 and 8 – Child-centred care in family context. Standard 8 - key worker to help family obtain services they need. Standard 2 – supporting parents. Standard 8 - specific information is provided to siblings of disabled children.

House of Commons Select Committee on Health Report, Head Injury Rehabilitation 2001 – co-ordination of services in the community.

Supporting people with long-term conditions, Dept of Health 2004, Ch 2 – case management; identify patients with complex conditions.

Chief Nursing Officer's review of the nursing, midwifery & health visiting contribution to vulnerable children and young people, Dept of Health 2004 – greater skill mix and more multi-disciplinary working.

House of Commons Select Committee on Health Report, Head Injury Rehabilitation 2001 – identifiable guide and advocate through the whole care pathway.

National Service Framework for Long-term conditions, Dept of Health 2004, quality requirement 5 - community rehabilitation and support.

Supporting people with long-term conditions, Dept of Health 2004, Ch 2 – support to stay at home.

	Journey	Children's NSF Theme
Support for V the Family	> As a result of the social (key) worker's assessment, a number of actions are planned. Care will be provided on a case management basis.	
	> Through their key worker, counselling is made available for Jack's parents and siblings, who are suffering great distress and anxiety at this time.	
	> They are reminded of contact details for 'Contact-a-Family' for additional support. They are also reminded again of the contact details for specialist ABI voluntary organisations and given contact details 'Road Peace' which provides information, support and advice for people who have been affected by a road traffic accident.	Standard 2 – Supporting parents; providing information and involving parents in care. Standard 8 -
	> The key worker (social worker) also provides advice about applying for benefits and assistance with filling in forms (eg. Disability Living Allowance, Carers Allowance, tax credits). She also provides information to the parents about Direct Payments, which can be used to provide flexible and individualised support.	key worker ensures access to services.
	> Jack's parents are also given information on the Family Fund. Jack's mother needs to learn to drive because public transport is poor and inaccessible in her area. The Family Fund agrees to pay for driving lessons.	
	> Jack receives visits at home from his school friends, organised by the class teacher, which helps maintain friendship and reduce social isolation.	
	> Short-breaks are provided for Jack so that his parents can spend time with their other children and have respite from caring for Jack.	Standard 8 – short breaks for children, young
	 > Jack is also offered a summer holiday with other ABI children, through an ABI charitable organisation, which is able to cater for their needs. He is delighted to take the opportunity. During his holiday Jack makes new friends who have ABI due to other causes. He notes that whilst they may need some different treatments, many of their rehabilitation needs are similar. They provide mutual support and encouragement and enjoy each others' company. 	people, parents and carers provide positive experiences and reduces stress.
	> Jack's siblings are offered the opportunity to attend weekend break, by the same organisation.	

NHS Improvement Plan, Dept of Health 2004 - *care of people with long-term conditions.*

Contact-a-family, Tel: 020 7608 8700 Helpline: 0808 808 3555 Email: info@cafamily.org.uk

Road Peace Tel: 020.8838.5102 Helpling: 0845.4500.355 email: info@roadpeace.org

Parents' Guide to Direct Payments – Council for Disabled Children 2004.

Carers and Disabled Act 2000.

Disability Discrimination Act 1995 – social inclusion of disabled people

National Service Framework for Long-term conditions, Dept of Health 2004, quality requirement 10 support for family and carers.

	Journey	Children's NSF Theme
Early provision of individual education needs	 > The LEA Hospital & Home Teaching Service make arrangements for an individual education plan, which includes a home teacher to visit Jack for short sessions 2-3 times a week, in the first instance. They explain to Jack's parents that the more detailed multi-disciplinary assessment (MDA) will be set up immediately by the LEA to ensure appropriate educational provision in the future. This involves gathering specialist reports (including hospital reports) to present to the MDA panel. > It also includes an early appointment for Jack to see an educational psychologist organised by the LEA, as requested in the paediatric clinical neuropsychologist's report. Close liaison between educational and clinical neuropsychologist is critical throughout the entire process. > The home teacher is able to provide assistance to help Jack regain confidence in his reading and writing skills, which were both affected by his injury. > The MDA Panel makes its assessment and grants Jack a Statement of Special Educational Needs. This assessment process is completed within 6 months 	Standard 9 – partnership working for children with psychological and special educational needs.
Statement of Special Education Needs	 > Jack's Statement of Educational Needs makes a number of educational and non-educational provisions, which comply with the SEN code of practice. Copies of the Statement are given to the parents and to teaching centre. Provision includes - > Gradual phasing out of the home teaching and to start attendance at the teaching centre and a gradual re-introduction to his mainstream primary school, depending on progress with Jack's physical, social, psychological and behavioural rehabilitation, > Teaching assistant support in lessons and breaks, > Whilst at the teaching centre, provision to allow attendance for rehabilitation, as required. > Special equipment, as advised by health professionals > The Statement is reviewed annually (with interim reviews, if required) when the provision can be amended, according to his changing needs. 	Standards 3 & 8 – Holistic care for children, which is flexible to their circumstances and needs.

Access to Education for children and young people with Medical needs. DfES, DH 2001

National Service Framework for Long-term conditions, Dept of Health 2004, quality requirement 4 - access and re-access

Special Educational Needs (SEN) code of practice 2001 www.teachernet.gov.uk/ teachinginengland/detail

Access to Education for children and young people with Medical needs. DfES, DH 2001 – flexibility to changing needs.

		Journey	Children's NSF Theme
Statement of Special Education Needs (cont.)	V	 > Arrangements are also made for Jack's school friends to visit him at the teaching centre. > Gradually, Jack's physical condition and strength improves. He is able to walk more confidently, although balance remains a problem. > His speech has improved over time and he no longer needs speech and language therapy input. > Jack's behaviour becomes calmer and his mood is less volatile. However, he is still very forgetful, finds difficulty in concentration and tires more quickly than his peers. > Strategies are developed with the aid of health professionals to help Jack, his family and the education service to support and maximise his abilities. 	Standard 8 – reduce social isolation. Standard 9 – mental health support for children at additional risk of mental health problems due to their special circumstances and/or disabilities.
Return to Primary School	~	 > In about 9 months time, at Jack's next annual review, it is agreed that he will try returning to his previous mainstream primary school on a gradual basis at the start of the next school year. He will maintain his links with the teaching centre for as long as necessary. > The LEA ensures that the primary school has a copy of Jack's statement. > Before Jack starts, the teacher at the teaching centre discusses his special needs with the head teacher and class teacher at his primary school and offers guidance on his reintegration. A number of current provisions are carried over to the school. Also - > school nurse to ensure all involved teachers have 	Standard 3 & 8 – co-ordination of care needs and appropriate sharing of information
		 appropriate information (with parents' permission), > liaison with therapists, > development of school healthcare plan, in discussion with family and school, > Individual learning support assistance is continued, > Jack to sit at front of class, due to his hearing loss, > Home/school diary is set up to assist daily planning and as a memory aide, > 'Buddy' system at school is considered, in order to help Jack re-integrate and find his way around school. 	Standard 3 & 8 – Continuity and co-ordination of care

House of Commons Select Committee on Health Report, Head Injury Rehabilitation 2001 – rehabilitation at a centre with specialised rehabilitation staff with expertise in brain injury.

Access to Education for children and young people with Medical needs. DfES, DH 2001

Supporting pupils with medical needs DfES/DH 1996 – school to be aware of pupil's needs before he/she starts school and to develop written healthcare plan in consultation with pupil, parents & health professions.

Chief Nursing Officer's review of the nursing, midwifery & health visiting contribution to vulnerable children and young people 2004 – Improved information sharing, nurse deployment and integration of services for vulnerable children.

	Journey	Children's NSF Theme
Injury prevention V & Road Safety	> Following Jack's accident outside the school gates, the school reviewed the provision of safety training on offer to children and the wider injury prevention measures.	Standard 2 – supporting parents in achieving the best outcomes for their children.
	 > The head teacher sets up discussion between representatives from all interested parties. The views of pupils, parents, staff, police, school nurse, PCT/public health, local authority (LA) road safety division are sought. As a result, a number of actions are proposed - > additional sessions from the LA at the local safety centre, which provides road safety and other awareness training for pupils and staff. > review and revise the school's travel plan, to encourage more children to walk and cycle to school and to reduce traffic congestion. The school decides to increase provision of safe cycle storage, provide less hazardous pick-up and drop-off points for cars and to consider setting up 'walking buses'. > The LA reviews the road layout around the school, increases the parking restrictions at the school entrance and looks at further road safety design features around the school entrance, including employment of a crossing patrol officer. > The LA and PCT agree to provide and fund more cycle training for children to the new national standards, > The school obtained agreement to be linked to the National Cycle Network to facilitate safe cycling to school. 	Standard 2 – good, high quality, timely support for parents as their children grow up is likely to improve outcomes for children and young people. Standard 1 – PCT and local authorities ensure that childhood injuries and accidents are reduced through development and monitoring of injury prevention strategies that target priority areas, where there are marked inequalities.
Secondary School V	 > Jack's statement is amended, naming his secondary school by 15th February in the year of transfer. > Visits to the new school are arranged in advance so Jack can familiarise himself with the new environment and staff. Education and school nursing staff from the 2 schools liaise to ensure that Jack's move from primary to secondary education is as smooth as possible. > In discussion with Jack and his parents, therapists and educational psychologist, the secondary school develop a new healthcare plan for Jack, building on the plan from his primary school. 	Standard 3 & 8 – integrated, co-ordinated care, which are flexible to changing needs and circumstances. Standard 4 – respecting and involving young people in their care.

Dept for Transport PSA target – to reduce the number of children killed or seriously injured by 50% by 2010, compared to 1994-8 baseline, especially in disadvantaged communities.

National Healthy Schools Programme to be promoted, especially in deprived communities, where number of childhood injuries is higher.

World Health Organization (WHO) 5-year plan for road traffic injury prevention 2002 – support for interventions which focus on vulnerable road users.

Choosing Health; making healthier choices easier, DH 2004, Ch 3 children and young people starting on the right path: - Active travel plan by 2010, - National Standard for Cycle training by 2006.

Supporting pupils with medical needs DfES/DH 1996 –

school to be aware of pupil's needs before he/she starts school and to develop written healthcare plan in consultation with pupil, parents & health professions.

	Journey	Children's NSF Theme
Secondary School V (cont.)	> Jack's statement of special educational needs is maintained throughout his time at secondary school and reviewed annually, with interim reviews, as required.	
	> Involvement of the paediatric clinical neuropsychologist continues during Jack's time at secondary school. This is an essential to ensure appropriate assessment and advice.	
	> Thus, Jack is enabled to remain in some mainstream classes and take part in suitable extra-curricula activities. This is made possible because the school has developed an accessibility plan, as required by DDA 1995, and has improved access and personal support for disabled pupils wishing to access after-school activities, which Jack finds beneficial.	Standard 8 – promote inclusion of disabled children and young people
	> However, Jack still has some enduring difficulties, including; concentration, memory, co-ordination, balance, unilateral hearing loss, fatigue, slowness and executive problems.	
	> Therefore, for additional support, Jack spends some time each week in the school's additional needs unit, where individual tuition is provided.	
	> Jack is gradually encouraged to take responsibility for using the coping strategies he has been practising.	Standard 4 – flexibility of services as young people develop into adulthood
	> The secondary school has developed an anti-bullying policy, which recognises the additional risk of bullying to children with disabilities. The school reassures Jack's parents that any hint of bullying is taken seriously and potential problems addressed.	
	> When he is aged 14 years, the local Connexions advisor is invited to attend his annual review (the transition review), to discuss his interests and options for future studies.	

Disability Discrimination Act 1995 – accessibility for disabled people.

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

Special Educational Needs (SEN) code of practice 2001.

		Journey	Children's NSF Theme
Growing up	¥	 > As Jack approaches the age of 16 years, he discusses with his parents, the school and his Connexions adviser (who is able to offer support until Jack is 25 years) the options for placements, courses and jobs. His OT is able to provide advice and support on appropriate adaptations. > Jack then decides to leave school and attend the local Further Education (EE) College which prevides witches and the local Further 	Standard 3 – integration between education/social and health needs
		Education (FE) College, which provides suitable part-time courses of interest to him.	
		> As Jack is going to FE college at the end of his compulsory schooling, the Connexions Service will carry out an assessment of his needs. This builds on what is already known about Jack and the provision, which will be required to meet those needs at FE college. Jack's Connexions personal adviser will liaise with the local Learning and Skills Council to ensure that appropriate provision is in place for him	
		> With Jack's agreement, his transition plan is transferred to the Learning & Skills Council (LSC) and the FE college, prior to his transfer.	Standard 4 – growing up, young person increasingly involved in decisions
		> With his Connexions advisor's support, Jack also finds a part- time work placement with a local retailer, within walking distance of his home. This encourages Jack's confidence and independence, whilst having the opportunity to develop further skills at FE college.	
		> Social Services explain to Jack that he can have direct payments rather than services for his own support needs from the age 16 years.	
		> Jack also continues regular health reviews with the paediatric neurologist. At the clinic, the nurse suggests the expert patient programme (EPP) to Jack and his parents. She provides the contact details on the web, for the family to obtain further information.	
		> With agreement for Jack and his parents, his GP, primary care, community and rehabilitation teams continue to exchange relevant information, as required, about Jack to facilitate a high standard of co-ordinated care.	

Access to education for children and

Learning & Skills Act 2000, section 140 – assessment.

Special Educational Needs code of practice 2000 - ch 9 annual review.

Connexions - Assessment, Planning, Implementation and Review framework (APIR) 2003 - support from personal advisor to develop a personal action plan for realising goals, based on holistic assessment of need.

Special Educational Needs Disability Act (SENDA) 2001 - to help disabled students to reach their full potential.

Expert patient programme – tel: 0845 606 6040 http://www.expertpatients.nhs.uk

	Journey	Children's NSF Theme
Transition to V adult services	> Jack's progress is reviewed on a regular basis with his paediatric neurologist and the rehabilitation team. This is important, particularly as Jack grows and develops because new difficulties may come to light as he becomes involved in new activities.	
	 Fortunately for Jack, the specialist rehabilitation service is equipped and staffed to cater for both children and adults. At the age of 18 years, the paediatric consultant suggests that it may now be the right time to think about transfer of Jack's reviews to the adult team in the same centre. 	Standard 4 – smooth transition to adult services.
	> Jack is assured that the process will be gradual, with opportunities to meet with members of both teams jointly, before formally transferring his care to the adult service. Jack is happy, feels he is ready for the transition and agrees to this arrangement.	Standard 8 - integration and co-operation between partners.

NHS Improvement Plan 2004, Ch 3 – people with long-term conditions to have more control over their care and to have the right level of support, individually tailored to their needs.





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