

RCPCH

Royal College of
Paediatrics and Child Health

Leading the way in Children's Health

PAEDIATRIC SERVICE SPECIFICATION

*Services for Children and Young People
following Acquired Brain Injury*

Contents

Purpose of the Service	3
National Context	6
Scope.....	6
Service Delivery	9
Service Outcomes	12

This service specification has been designed to assist commissioners in the delivery of services for children and young people following Acquired Brain Injury.

The specification is not mandatory - it is designed to help implement existing guidelines and should be review and amended to ensure that it meets local needs.

This specification has been developed by the RCPCH in conjunction with BACD, BACCH and BPNA colleagues.

Purpose of the Service

Aims of the service

The Acquired Brain Injury (ABI) service aims to provide optimal family-centred health care for all children and young people who experience ABI with the ultimate purpose of improving their physical, mental and emotional health, and overall quality of life. A key aim of this specification is to provide a framework for local care, following the acute treatment phase, through which children and young people may achieve their full rehabilitative capacity.

The service also aims to allow children, following ABI, to maximise their physical, educational and vocational potential, through multi-agency working with educational, social care and other services.

Key objectives of the service

The objectives of the service are to:

- Improve health outcomes to ensure the full participation of children following ABI and their families in their communities
- Provide care that is safe, effective and evidence-based (or based on international consensus on best practice where evidence base is limited)
- Ensure health care services after the acute phase of care for children and young people following ABI are coordinated with the full array of mental health, educational, social, and other community-based services needed by and provided to children and young people and their families.
- Ensure that children and young people following ABI, and after the acute phase of care, receive their care as close to home as possible.
- Reduce inequalities in outcome due to regional differences in the provision of services to children and young people following ABI.
- Enhance development and functional outcomes for children and young people following ABI, and improve family life, through appropriate and ongoing access to rehabilitative services, monitoring for known complications following ABI and the delivery of effective, outcome-based, high-quality medical care.
- Ensure effective and seamless transition of care from children's to adult health services where required, and to maximise the young person's understanding of their condition and optimise their autonomy and ability to manage their health care.
- Support parents and families in meeting their responsibilities to nurture and to enhance their child's development.

- Ensure equity of access, quality, consistency, and accountability in the service system by ensuring clear lines of responsibility for the provision of health services to child and young people following ABI.
- To raise awareness of the consequences of and the needs of children and young people and their families following ABI (particularly those which may be considered “invisible”, e.g. behavioural problems, and a potential source of stigma) through promotion of joint training with other agencies.
- Promote clinical governance, a quality improvement culture and involvement in research among services for children and young people following ABI in order to assure and continuously improve the quality of care for children and young people following ABI.

What is *Acquired Brain Injury*?

Acquired brain injury (ABI) is brain damage caused by events *after* birth to a brain which is assumed to have the potential for normal development rather than as part of a perinatal insult, genetic or congenital disorder. The aetiology of ABI is most commonly is traumatic (TBI), but can be post-neurosurgery, post-infective (e.g. meningitis, encephalitis), poisoning, brain tumours, hypoxaemia, hypoglycaemia or other severe metabolic condition, ischaemia and occasionally of unknown origin.

ABI can affect all of the functions of a brain, not just the physical but also the cognitive and emotional. ABI may result in sensory impairments and autonomic instability, resulting in problems with blood pressure and heart rate. These affects may be temporary or permanent, and may continue to evolve or to emerge some time following the injury, e.g. post-traumatic epilepsy, requiring on-going monitoring.

Why is there a need for specified services for children and young people following ABI?

There is no simple relationship between hospital attendance or admission and ABI severity and morbidity. Children and young people with mild or moderate ABI who may not have been admitted to the Paediatric Intensive Care Unit (PICU) may still have significant on-going needs which can have major effects upon their education, social interactions and behaviour. This group of young people are at risk from school exclusion and often have a disproportionately higher likelihood of becoming involved in the criminal justice system after their injury¹. Furthermore, children and young people from lower social classes are both more likely to be injured, and more likely to

¹ Repairing Shattered Lives (Barrow Cadbury Trust 2012)
www.bctrust.org.uk/wp.../10/Repairing-Shattered-Lives_Report.pdf

have poor health outcomes, an unacceptable result of the inequalities within the current system²

In both traumatic- and non-traumatic ABI children and young people often have pre-existing co-morbidity which has contributed to the development of ABI and may complicate recovery, e.g. clotting abnormalities, sickle cell disease etc. For TBI behavioural and developmental co-morbidities, e.g. Attention Deficit Hyperactivity Disorder, are similarly more common. Non-traumatic ABI may arise as a consequence of medical interventions such as chemotherapy or following neurosurgical procedures (e.g. tumor removal). Regardless of the cause of ABI for the individual child/young person, there are common morbidities and needs for the child/young person and their family which must be addressed.

At present there is a mistaken perception that children and young people have better outcomes than adults from a comparable brain injury. This is not the case, giving rise to unrealistic expectations for a child/young person's recovery and an under recognition of the need for comprehensive service provision following ABI

² Injuries in Children Aged 0-14 years and inequalities. A report prepared for the Health Development Agency (HDA 2005)
www.nice.org.uk/niceMedia/pdf/injuries_in_children_inequalities.pdf

National Context

Prevalence

Traumatic ABI (TBI), e.g. following a fall from a height or road traffic accident, has been estimated to result in significant new disability in approximately 20 per 100,000 children under 16 annually, with NICE estimating ~300,000 attendances to A&E with head injuries in children and young people under 16 years of age. The incidence of moderate to severe TBI is ~2.5 times higher in rural compared to urban populations³. The two peaks in childhood are in children aged five years or younger and then in the teenage years. TBI accounts for 5.6 admissions to PICU per 100,000 of population. Estimated hospital admission rates for children under 14 per year in the UK range from 150,00 to 500,000.

Approximately 25% of the ABI acquired below the age of five, and the majority below the age of one, is of non-accidental origin. Strokes occur in 1.3 to 13.0 children per 100,000 a year. The incidence of coma following non-traumatic brain injury has been estimated at 30.8 per 100,000 children and young people per year⁴. A number of rare disorders in childhood, e.g. metabolic conditions, may give rise to ABI, requiring highly specialist management of the underlying condition.

Evidence base

This specification draws its evidence and rationale from a range of standards, guidance and frameworks including:

- The 'Management of Children with Major Trauma NHS Clinical Advisory Group Report, February 2011'.
- Children's Neurosurgical Services in England: a Framework for the Future 2010, Children's Neurosurgical Specifications Standards. May 2011:-
- Children and Young Peoples outcome Forum 2012
- Children and Young Peoples outcome forum 2012
- Kennedy Report 2010 & Green paper 2011
- Children and Young People Health Outcomes Strategy (2012)
- Standards from Faculty of Paediatric Neuropsychology (Middleton 2012)

³ Feigin VL et al "Incidence of Traumatic Brain Injury in New Zealand: a population based study" Lancet Neurology 2013 12(1):53-64

⁴ Wong et al "Incidence, aetiology and outcome of non-traumatic coma: a population based study" Arch Dis Child 2001 Mar;84(3):193-9

Scope

A locally based Multidisciplinary Team (MDT) service should be provided for all children and young people (under the age of 19 years) following ABI, within a network linked with the tertiary centre for:

- Children's Trauma
- Children's Neurology/Neuroscience
- Adult Rehabilitation Team

The Local MDT team is responsible for developing and implementing these important components of the local ABI service:

- The ability to rapidly respond to the sudden change in circumstances for children and young people and their families—this is one of the main differences in ABI rehab provision compared with care for a child with a developmental neurodisability
- Effective and timely communication amongst key service providers, including tertiary services, specialist rehabilitation services, and local hospital and community paediatric services.
- Provision of a key worker with responsibility for liaison with the tertiary centres for individuals and families
- Provision of intensive multidisciplinary rehabilitation when needed which for some children and young people may be residential
- Provision of 'support and information' for families involved in ABI, including access to social care and disability benefits. This should begin at diagnosis, through to return to home and community life and beyond
- Provision of a key worker for families within their community services, which does not necessarily need to be the paediatrician.
- Liaison with and training in schools for the specific needs of children and young people with ABI
- Liaison with specialist medical services involved in the care of any pre-existing conditions which may have pre-disposed to ABI, e.g. sickle cell disease, clotting abnormalities, metabolic disorders.
- Provision of skilled cognitive assessment to inform education and behaviour management (a clinical or educational psychologist with additional neuropsychology training is highly desirable). Cognitive impairment may not be immediately obvious but may need addressing some years after injury
- Training at the local level for health care, social service and educational professionals who will come into contact with children and young people following ABI

Interdependencies with other services

All services will work directly with, but not limited to, the following professionals to ensure a seamless service:

- Adult rehabilitation
- Audiology
- Speech and Language Therapy
- Child and Adolescent Mental Health services
- Orthotics
- Physiotherapy
- Occupational Therapy
 - Medical specialists (as required and depending on local arrangements), including, but not limited to: Paediatric Neurology Paediatric Epilepsy Paediatric Orthopaedics General Paediatrics Paediatric Endocrinology Paediatric Gastroenterology Paediatric Surgery

Service Delivery

1. The locality MDT service should be provided by a specialist consultant- led multidisciplinary team working in collaboration with colleagues in other specialities and agencies, e.g. education, mental health, social care and the third sector. This is to ensure that the full range of specialist professionals trained in the effects of ABI are available for appropriate assessment and provision of care for children and young people who have the range of complex physical, behavioural, psychological and cognitive/learning problems that may follow ABI.
2. The locality MDT service should include physiotherapy, occupational therapy, speech & language therapy, dietician, clinical psychology, collaborative working with mental health services and appropriate voluntary organisations with particular expertise in ABI in children and young people. If expertise in managing ABI is not available within any of these locality professional groups then it would need to be accessed and made available through the network eg neuropsychology.
3. The paediatric consultant leading the MDT should have particular expertise and training in ABI and its effects on children and young people but is also likely to be the consultant managing a range of neuro-disabilities requiring both habilitation and rehabilitation in the home and the community.
4. Provision of intensive rehabilitation when needed including access to facilities for residential rehabilitation.
5. Provision of equipment, including communication assessments and AAC, should be without delay
6. Data collection on outcome from ABI should form part of the service
7. Arrangements for planned transition to adult services should be in place including adult rehabilitation teams where appropriate. This process should be initiated in a timely fashion in early adolescence, with a key worker identified for each individual child/young person to coordinate the process.^{5, 6}

⁵ Transition: Getting it Right For Young People (DH, 2006).
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4132145

⁶ Lost in Transition: moving young people between child and adult health services (2007 RCN)
http://www.rcn.org.uk/_data/assets/pdf_file/0010/157879/003227.pdf

Applicable national service standards

The service will implement best practice guidelines and quality standards in order to standardise care across local and regional networks. Examples include:

- The National Service Framework Standards for children with disability and long term conditions (Standard 8) , the mental health and Psychological well-being of children and Young People (Standard 9) 2004 (inc. Jack's Journey)
- The 'Management of Children with Major Trauma NHS Clinical Advisory Group Report, February 2011'.
- Children's Neurosurgical Services in England: a Framework for the Future 2010
- Children's Neurosurgical Specifications Standards. May 2011:-
- Children and Young Peoples outcome forum 2012
- Kennedy Report 2010 & Green paper 2011
- Children and Young People Health Outcomes Strategy (2012)
- Standards from Faculty of Paediatric Neuropsychology (Middleton 2012)

Additionally, the following general standards for children's health care are of particular importance for children and young people:

- Essential Standards of Quality and Safety, Care Quality Commission, London 2010 underpinned by Safeguarding Children and young people Intercollegiate guidance for healthcare staff RCPCH, RCN, RCGP et al 2010
http://www.rcn.org.uk/__data/assets/pdf_file/0004/359482/REVISED_Safeguarding_03_12_10.pdf
- See also Working Together to safeguard Children HM Government 2010 (superceded 2012)
<https://www.education.gov.uk/publications/standard/publicationdetail/page1/D/CSF-00305-2010>

All children and young people who use services must be

- Fully informed of their care, treatment and support.
- Able to take part in decision making to the fullest extent that is possible.
- Asked if they agree for their parents or guardians to be involved in decisions they need to make.⁷

When children and young people following ABI who use paediatric services are moving to access adult services, these should be organised so that all those involved in the care, treatment and support cooperate with the planning and provision to ensure that the services provided continue to be appropriate to the age and needs of the person who uses services.⁸

⁸ Transition: Getting it Right For Young People (DH, 2006).

Service Outcomes

- To optimize the quality of life for children and young people with ABI and their families through provision of a high quality health care service.
- To ensure children and young people with ABI are treated according to evidence-based or best practice guidelines.
- To ensure equitable delivery of care for all children and young people with ABI, as close to home as possible
- To ensure coordination of health, education and social care as required for children and young people with ABI
- To ensure routine and systematic data collection on performance of each service, and publication of data to allow meaningful comparison among services, ultimately leading to improvement in governance and quality of all local services
- To ensure safeguarding and all other statutory Trust and NHS procedures are complied with

Specific Indicators

Specific Indicators should include:

- Evidence of Pathways of care from acute to rehab phase – including communication and continuation of the rehabilitation prescription
- There should be children’s rehabilitation and care coordinator posts through the network. They should work with multidisciplinary children’s rehabilitation teams in a networked model to allow care close to home as soon as possible.
- Each Network should identify a named lead consultant in paediatric neurodisability centrally and locally.
- A key worker must be identified within the network for each family. A key worker should be identified during hospital admission.
- Following transfer after the acute phase to either local hospital or community services a member of the local ABI team should have met with the child/young person and family within one working week.
- Each child/young person following ABI should be provided with an individualised rehabilitation programme, including agreed outcomes and goals. There should be evidence of a regular review of this programme, the frequency of which should be dictated by the progress of the individual child/young person.
- Local MDT rehab members should have availability for rapid response to ABI (i.e. within 72 hours), liaison with tertiary services, support for family and specific therapeutic input for intensive rehabilitation where needed.
- Neuropsychology services should be readily accessible for children and young people with traumatic brain injury. Each child/young person with an ABI should receive:

- a) A comprehensive clinical neuropsychological assessment which outlines their specific functional, cognitive, behavioural and emotional strengths and weaknesses;
 - b) Written recommendations on how they, their parents and school might manage their difficulties in the rehabilitation/educational process
 - c) Each family of a child/young person with an ABI will be assessed for their individual/family emotional and social needs.
- There should be network-wide school re-integration policy for children and young people following major trauma and traumatic brain injury. A specialist rehabilitation team should advise on school needs.
 - Early and regular contact should be made with the local hospital and community paediatricians, general practitioner and local multidisciplinary team so they can be involved in planning the long-term care of the child/young person from an early stage.
 - Vital rehabilitation equipment, including appropriate wheelchairs and mobility devices and home adaptations, should be made available as soon as possible and not delay the child's return home.

NHS outcome indicators applicable to ABI

The Trauma Audit and Research Network (TARNlet):

- Time from decision to transfer a child to time of arrival at treatment centre
- Time from 1st contact to definitive treatment for CYP with head injury
- Incidence of moderate/major trauma as measured by index severity score

Evidence of regular liaison between tertiary and district care teams during a CYP admission to a tertiary centre.

Time between readiness for transfer from tertiary to district care and transfer occurring.

Time between decision to transfer to specialist rehabilitation service and transfer occurring

Time between readiness for discharge home and discharge occurring

Measure of functional recovery 1-2 years after discharge from PICU for children and young people ABI, e.g. Gross Motor Function Classification System (GMFCS), Manual Ability Classification System (MACS), the Functional Independence Model for Children (WeeFIM), King's Outcome Score for Child Head Injury (KOSCHI), etc. It is essential that outcome measures used include consideration of educational performance/level of educational support required, and map across the International Classification of Functioning, Disability, and Health Framework (ICF).

Each child or young person with a long term condition, disability, special educational needs, looked after or a care leaver, has a coordinated package of care, including a quality assessment, access to key working approach and timely provision of appropriate equipment

Any child/young person in transition from paediatric to adult care should have a defined and agreed plan for handover of care with access to a key worker.

Location of Provider Premises

The MDT work can be undertaken in a variety of settings but should be appropriate for the individual needs of the child or young person and family such as outpatients, schools, homes and inpatient settings.