

Regional Acquired Brain Injury Implementation Group (RABIIG)

Acquired Brain Injury Pathway for Children & Young People



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1.0 Introduction

1.1 Background

The Regional Acquired Brain Injury Action Plan was launched by the Minister for Health in June 2010 and will be implemented via the Regional Acquired Brain Injury Implementation Group, chaired by Mr Kevin Keenan, Assistant Director Social Services, Health and Social Care Board. The Action Plan for Acquired Brain Injury (ABI) builds on the Review of Services for People with Acquired Traumatic Brain Injury in Northern Ireland (September 2008). The purpose of producing this Action Plan on Acquired Brain Injury is to provide clear time-bounded targets to drive service improvement and to co-ordinate action in order to improve outcomes for patients, their families and carers.

Throughout the document any references to 'people' or 'patients' refer to children and young people up to the age of 18 years or 19 years if the young person attends special school. The action plan falls into four key themes:

- Service Redesign
- Quality Improvement
- Improved Support for Individuals, Carers and Families
- Effective Engagement and Partnership Working

1.2 Definition of Acquired Brain Injury (ABI)

Acquired Brain Injury (ABI) is defined as an injury to the brain caused by an identifiable event such as trauma, hypoxia, metabolic disorders or infection. The term does not include brain injuries that are congenital or induced by birth trauma. It also does not include progressive brain disorders and those that are acquired over time due to alcohol and drug misuse.

Those accessing care through Acquired Brain Injury Services will have an injury as outlined above. However, it is recognised that clinical judgement will be required for a number of people with exceptional, complex presentations to be cared for on a 'case by case' basis in partnership with other services. This will require Trusts, as outlined in Recommendation 2 of the Service Standards and Quality Indicators document, to develop joint care protocols with Stroke, Mental Health, Addictions, Forensic and Core Disability Services. These protocols must include escalation arrangements for when agreement cannot be reached regarding the most appropriate service intervention(s).

While stroke is classified as an acquired brain injury, separate standards/guidelines and services have been developed for stroke survivors and are therefore not dealt with in this document. In the case of children with stroke, care will be provided through the Children's ABI Pathway as no children's stroke services are currently available.

The majority of ABI patients suffer a Traumatic Brain Injury (TBI) and within this group the larger number will have received a mild or moderate injury that does not require inpatient treatment or rehabilitation. Standards are included for such groups of individuals.

1.3 Strategic Drivers

Whilst legislation alone is a key driver for change there are also a number of government policy documents, service frameworks, action plans, reports and guidance which collectively define the responsibilities and obligations placed on the Department of Health, the Health and Social Care Board and the Health and Social Care Trusts. Some key legislation and documents are listed below:

- The UN Convention on the Rights of Persons with Disabilities 2008
- The UN Convention on the Rights of the Child 1991
- The Northern Ireland Act 1998
- The Human Rights Act 2000
- The Disability Discrimination Act 1995
- The Children Order (Northern Ireland) 1995
- The Children's Services Planning Order (Northern Ireland) 1998
- A Healthier Future 2005 - 2025 (DHSSPS)
- Disability Discrimination Act 1995
- Chronically Sick and Disabled Person Act 1970
- Report of the Promoting Social Inclusion Working Group Report on Disability 2009
- Priorities for Government
- Families Matter 2009 DHSSPS
- The Carers and Direct Payments Act (Northern Ireland) 2002

1.4 Guiding Principles – What Children and Parents Can Expect

The development and implementation of this Care Pathway is based on agreed guiding principles. These include:

1. The promotion of a child and family centred pathway, which focuses on improving access, timely assessment and tailored family interventions.
2. Reduction in waiting times from referral to assessment and follow on support.
3. Clear information about care and care services including those provided by the independent sector.
4. Integrated health and social care, which is co-ordinated between inpatient and community rehabilitation services. There are also specialist ABI independent sector organisations that provide services.
5. Streamlined (single) referral access points and more equitable services.

6. A comprehensive assessment of needs, and involvement in all care decisions.
7. Flexible personalised care, which addresses needs, as resources permit.
8. Ensuring individually appropriate tailored information, communication and support for children and their families.
9. A written and shared care plan which includes clear details of care being provided by all those involved in its provision.
10. Regular multidisciplinary reviews.
11. Carer assessment.
12. Effective transitional care and support.
13. Upon discharge from services, contact information to re-engage support if needed on a fast tracked basis. This should form part of discharge planning.

1.5 Values

Whilst this pathway reflects the associated Brain Injury Service Standards and Quality Indicators document, there are a number of key values that pertain to children and their carers which have become accepted as the norm for all children's services. These are:

- Children are best cared for at home and within families where possible.
- The ordinary needs of children and families have to be met as well as their special needs.
- Parents know their child better than anyone else and must be treated respectfully by professionals as equal partners given the expertise they have in the care of their child.
- Professional supports must be co-ordinated and responsive to the needs of individual children and families.
- Risks to the child's life need to be managed in ways that provide safety and a good quality of life to the child and family.
- Partnership working across disciplines and agencies is essential.

1.6 The Model

The pathway incorporates local and regional considerations and reflects many principles included in the *DHSSPS Integrated Care Pathway for Children and Young People with Complex Physical Healthcare Needs* (DHSSPS ICP CWCHN, 2009), the *National Managed Clinical Network's Children with Exceptional Healthcare Needs* (CEN) pathway used for children aged 0-19 years and the *Standards for Disabled Children in Hospital* (Office of Social Services, 2010).

2.0 Care Pathway

The purpose of the pathway is to improve and develop services for all children up to the age of 18 years (aged 19 years if attending special school) with ABI in Northern Ireland. The DHSSPS Action Plan highlights from the outset that there are particular issues and concerns regarding existing services for children.

The pathway addresses mild to moderate and moderate to severe Acquired Brain Injury.

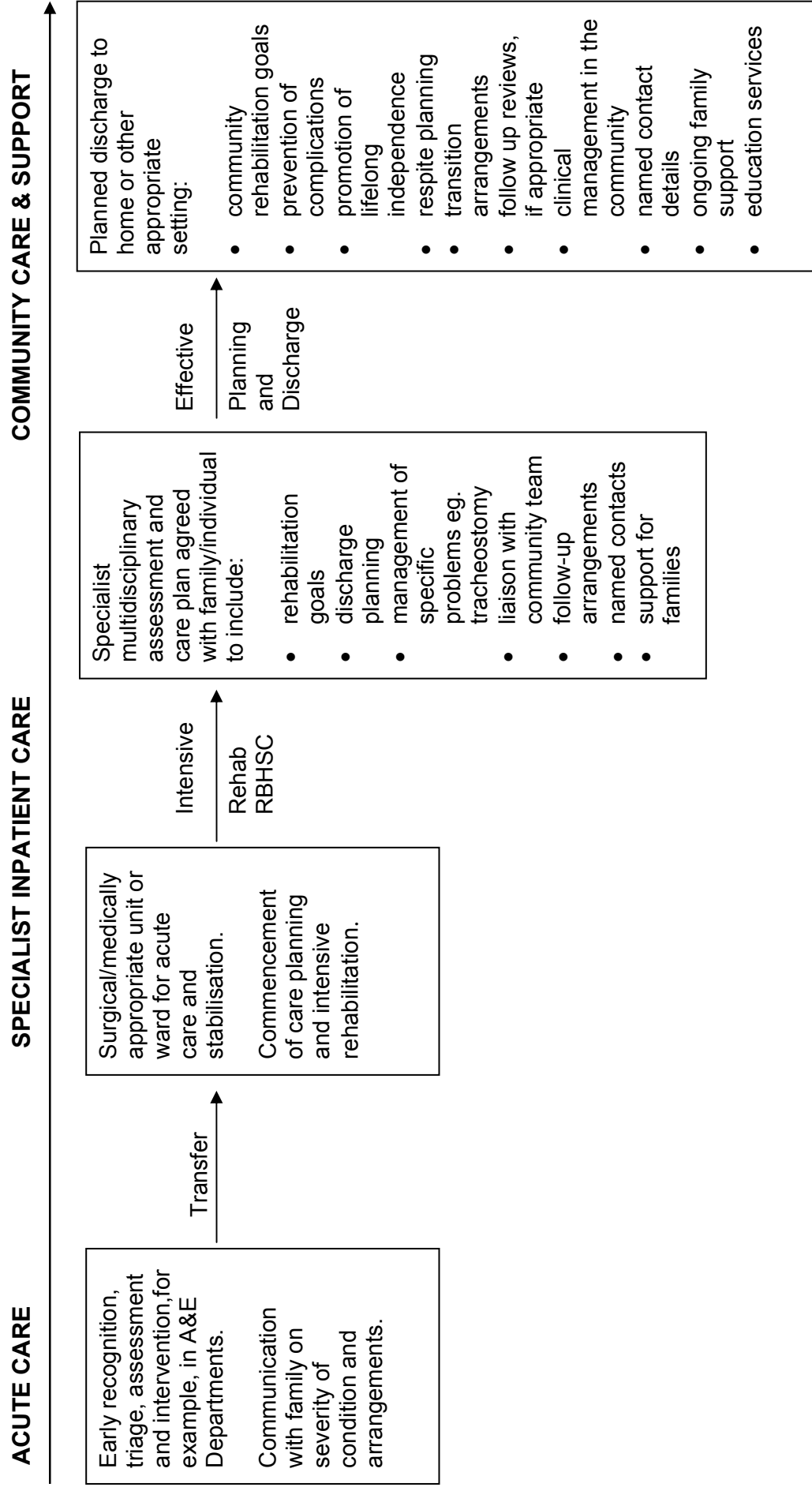
The Department of Health (DH) and Department of Education and Skills (DES) in 2004, as part of the Every Child Matters programme, developed the *National Standards Framework for Children, Young People and Maternity Services*. One of the specific exemplars provided was that for children with Acquired Brain Injury *Jack's Journey* (DH/DES, 2004) which in essence followed a child and his carer's journey through services following an acquired brain injury:

Acute hospital care is available across all the age ranges. However, whilst there are four inpatient rehabilitation units and five Community Brain Injury Teams across Northern Ireland for adults, access for the over 65s has been equivocal and there are no regional or Trust wide community brain injury teams for children. The Care Pathway for children will therefore be required to focus on the services available through existing core services in children's services, and in the development of protocols in working across programmes of care into adult services. It has been agreed that Adult Community ABI Teams will work closely with colleagues in Children's Community Disability Services in respect of children who have an ABI from the ages of 16 years to offer both a seamless transition to adults services and also to offer specialist advice on the management and support of ABI if this is required.

There are five main phases to the pathway:

- Identification – presentation at acute/non acute settings
- Early acute management of care
- Post Acute Specialist Inpatient Rehabilitation
- Community Care and support through Children's Services
- Transition to Community Brain Injury Teams

Figure 1: Care Pathway – Moderate to Severe Acquired Brain Injury



2.1 Admission/Acute Presentation

Upon admission to acute settings, likely via Accident & Emergency Departments, staff should focus on the need to consider the early recognition and assessment and treatment of acquired brain injury. Clinical staff including ambulance staff should be aware of the National Institute for Clinical Excellence (NICE) *Head Injury Assessment Investigation and Early Management of Head Injury in Infants, Children and Adults* and the Joint Royal Colleges Ambulance Liaison Committee (JRCALC) *Clinical Practice Guidelines: Paediatric Trauma Emergencies*.

Consultation with the appropriate paediatric staff by A&E staff should occur, as not all acute A&E Departments will have access to Paediatric A&E.

The support of and provision of information to parents/carers is vital from the initial processes of admission as is the provision of clear concise and non-jargonised information. The opportunity to discuss all aspects of care and prognosis should be available to carers and parents.

Breaking difficult news is an essential part of the pathway for children with exceptional healthcare needs including ABI because it is often a recurrent feature in the lives of these children and their families and this process might be revisited at a number of stages in their lives. The following will be useful in assisting in the sharing of information and in engagement with parents/carers:

<http://www.cen.scot.nhs.uk/files/4a-framework-for-sharing-significant-news.doc>

http://www.cen.scot.nhs.uk/files/4b-breaking_bad_news-ireland.pdf

2.2 Inpatient/Acute Care

Following initial admission and intervention, the planning process in respect of the most appropriate unit/ward for acute care and intervention, will commence. Children who have suffered a moderate to severe injury will be assessed by an appropriate medical consultant and if necessary transferred to the Royal Belfast Hospital for Sick Children (RBHSC) for children up to age 13 years. Young people over the age of 13 years can be admitted to adult wards. Trusts are required to follow the regional protocol which sets out the standards for admitting young people onto adult.

It is at this stage of the pathway that commencement of care planning and intensive rehabilitation provision should begin. For children and young people transferred within the acute admission environment, the

relevant setting must have in place clear local procedures to ensure timely access to relevant services to support rehabilitation. The retention of a child/young person in such acute settings must clearly be determined on need, and not on the basis of unallocated services.

The inpatient environment includes provision for the assessment and management of cognitive, behavioural, physical, psychological communication and functional difficulties.

For those children remaining as inpatients within the acute hospital of admission, and where there is an acquired brain injury or concerns in respect of such, consideration should be given to consultation with the specialist regional paediatric neurology services in respect of advice regarding care management and possible referral as inpatient or post discharge outpatient.

Those children requiring specialist inpatient services should be referred to the regional service at the Roylea Belfast Hospital for Sick Children and the appropriate transfer protocols adhered to. A small proportion of children/young people will require transfer post admission to the regional specialist centre for acute care for specialist clinical and rehabilitative supports in respect of their head injury.

It is acknowledged that at present there is not a dedicated unit for rehabilitation of childhood brain injury. However expertise can be accessed in the Children's Hospital in the Belfast Trust including neurosurgical, neurology, neurodisability and therapy based input as well as availability of specialist psychology services.

The pathway for children/young people with ABI will require the provision of dedicated resource in specialist settings for children/young people with ABI. The minimum level of provision should be four dedicated beds from within existing services. This figure has been derived from the scoping and demand capacity exercises undertaken as part of this pathway development.

The provision of the dedicated beds for children and young people should be in compliance with Part XVII of the Children Order (Northern Ireland) (1995) and with DHSSPS NI correspondence in respect of placement and safeguarding arrangements for children/young people within hospital settings.

Regardless of inpatient facility, in all cases where inpatient services are required, and where concerns or a clear diagnosis in respect of an ABI exist, a full multidisciplinary assessment and care plan should be undertaken and a key worker identified to take responsibility for co-ordination of the care plan and liaison with the family/carers agreed. The care plan should include:

- Rehabilitation goals and services identified to progress management of specific medical needs.
- Review arrangements for the child/young person and future dates of review meetings agreed.
- Agreement by all professionals and by the carers/parents.
- The needs of carers should also be considered and the option of a carer's assessment offered.

Further guidance in relation to multi-agency and multidisciplinary assessments can be found at Appendix I, Page 23, *National Service Framework for Children, Young People and Maternity Services*, most notably Standard 8: Disabled Children and Young People and Those with Complex Health Needs.

Guidance can also be found in the *Understanding the Needs of Children in Northern Ireland (UNOCINI) Framework* and the *DHSSPS Integrated Care Pathway for Children and Young People with Complex Physical Healthcare Needs* (DHSSPS ICP CWCHN, 2009).

For those children/young people placed in specialist settings outside of their Trust of origin, their Care Plans and their Key Worker arrangements should be agreed and an identified member of staff from the Trust of origin identified at time of admission to the specialist unit will liaise between Trusts and as identified lead in transfer and discharge planning.

For the small number of children/young people placed outside of this jurisdiction on the basis of extra contractual referrals (ECRs), a similar planning process must be established and should be clearly defined in the Service Level Agreements (SLAs) with such providers.

Discharge Planning

Discharge planning will form an integral part of care within the acute hospital setting and should be commenced from admission.

- Protocols should be in place to allow for the transfer of patients to other specialist rehabilitation units or a return to local acute hospital facilities from an out of area placement, as patient needs change.
- There is a designated member of the MDT/IDT to co-ordinate the discharge process and take responsibility for making and maintaining links with the relevant community services.
- A risk assessment will be carried out as part of discharge planning.
- At an early stage patient's, families and carers' needs for post-discharge services are assessed and a mechanism is put in place for onward referral to these services (eg. social care or core outpatient services, CBITs).
- An immediate discharge summary is provided to the patient and GP and community paediatrics giving diagnosis and medication.

- Discharge/transition reports are sent to the patient's GP and other health professionals and are available to the patient and, with their consent, their family/carers within 10 working days of discharge. This report should contain information regarding:
 - Nature/history of injury
 - Assessment results
 - Progress made
 - Interventions provided
 - Current needs
 - Key contacts
 - Responsible services/professionals for future care/therapy.
- For the discharge of a patient from inpatient rehabilitation, there will be clear and agreed processes in place for the handover of care to children's core community services.
- Essential equipment should be provided to the family/carers before the transfer takes place.
- Competency based training, with underpinning knowledge, should be initiated and overseen by hospital staff and completed for essential carers (including family members) prior to discharge.
- A 24 hour contact number(s) should be provided for the family for emergency health care needs post discharge. Ideally this should enable contact with community staff (if available) or with ward staff in the acute hospital.
- A home visit from community staff ideally should take place on the day of discharge or if not possible, a phone call is made followed by a visit the next day.
- A care co-ordinator will be identified to work in partnership with other services to provide a suitable service plan.

The Support Plan agreed prior to the transfer should be reviewed within two weeks of the child's transfer and thereafter at agreed intervals. The Discharge Co-ordinator from the acute setting should be invited to the first review.

The relevant amendments and notifications to the Child Health information system and module V of such should also be undertaken to ensure identification on that database of a child/young person with additional needs.

2.3 Community Care and Support

In the absence of specific statutory services designed to holistically meet the needs of children with ABI, there are various services and pathways through which the child and family currently navigate, depending upon individual needs. These include the following:

- Complex Needs Pathway
- CAMHS/Paediatric Psychology Service
- Learning Disability Teams
- Paediatrics/CDCs/Physical Disability Teams
- Education

There should be clear step-down/transitional protocols from acute to community services in each Trust area. These should cover both transfer from regional specialist provision to local acute hospitals and/or community settings.

The planned discharge of a child/young person to home or an alternative appropriate setting should be led by Children with Complex Needs Co-ordinators or an equivalent clinical staff member. This must include the following components:

- community rehabilitation goals
- prevention of complications
- promotion of lifelong independence
- respite planning
- transition arrangements
- follow up reviews, if appropriate
- clinical management in the community
- named contact details
- ongoing family support

All Trusts should have a clear documented referral system for the provision of services following a brain injury. A home visit from community staff (as agreed at the pre discharge meeting) should, as a minimum, take place on the day of discharge or, if not possible, a telephone call, followed up by a visit the next day. Each child/young person's plan will be:

- Led by professionals with experience in brain injury; a lead consultant should be identified as part of the discharge plan and a lead liaison identified within the Trust
- Goal directed
- Tailored to meet the needs of each patient and their families/carers
- Involve the individual, families/carers
- Reflect their needs within the community
- Delivered on a one-to-one or group basis

The rehabilitation programme will be flexible to meet the changing needs of the patient and carer/family as recovery occurs (including psychological adjustment/insight). Each patient/family will have a designated key worker/lead therapist who will take a lead role in the case and in supporting the patient and family.

A copy of the rehabilitation plans will be provided to the patient's family, GP and other relevant professionals and will be reviewed with the key worker and patient/carer initially at three monthly intervals. A formal review with the patient will be undertaken within an agreed timeframe and according to patient need.

There should be a community in-reach to the family in hospital preferably via visit or telephone. Services will be provided through existing Children's Community Services and Education Services in partnership with relevant voluntary providers (eg. Child Brain Injury Trust and/or Cedar where arrangements exist as part of any SLA with the young person's Trust of origin).

Competency based training, where required, should be initiated and overseen by hospital staff and completed for essential carers (including the family) before discharge. Clear lines of communication should be agreed between all parties before discharge. All carers will be offered an assessment to determine their needs.

Community Services

Prior to discharge from acute to community services the care plan should identify the core services in community children's services required to provide support and rehabilitation. These may include a named Consultant Community Paediatrician, AHP Services, Social Services, CCNs, Clinical Psychology and Educational Psychology. The provision and availability of these services should be in place at the earliest possible date following discharge.

Community Paediatrics and Child Development Clinics (CDCs)

Prior to discharge notification and referral to community paediatrics services and or Child Development Clinics is required. Upon discharge access to a named paediatric service will be arranged for the child/young person as part of the case plan and clear roles for staff from CDC/core community services should be agreed and put in place. This will be required to ensure that the appropriate linkages with Education Services can be progressed and that the relevant functions of health and social care paediatric services in relation to the *Code of Practice on Identification and Assessment of Special Educational Needs* (Department of Education, 1998) are adhered to.

Child and Adolescent Mental Health Services (CAMHS) Children's Psychological Services , ASD Diagnostic Clinics and ADHD Clinics

While most children/young people will enter the pathway following presentation at an acute setting following an incident of trauma where a head injury or suspected ABI has occurred. There is the potential that

some children/young people with a moderate ABI, where the impact has not been identified previously or where there has been deterioration in behaviours and functioning, may be referred to CAMHs or other diagnostic services/clinics. In all cases where children/young people are referred to such clinics a full clinical history will be taken and if this history indicates concern regarding ABI the Trust Paediatric Neurologist should be considered for advice, and onward referral if required. In Trusts where neurology support is not available to children's services advice should be sought from the regional centres prior to provision of clinical interventions.

Education Services

The service which is accessed by children for the predominant period of their childhood is that of education. Schools are the primary service in children's lives and have been hugely important in intervening and adjusting for the ongoing physical, cognitive and emotional/behavioural needs of children with ABI. This report acknowledges that the role for Education Services in any pathway for children with ABI is crucial. While the ABI pathways for children have been developed within health and social care the interface with statutory Education Services is central to the progression of any case plan and service provision.

The challenge that ABI poses for the Educational Sector is significant. In the case of moderate to severe injury it involves, but is not confined to, comprehensive communication between health and social care services and school, accessing appropriate support and raising staff awareness and skill level regarding ABI.

In cases of moderate to severe injury where hospitalisation has occurred, a starting point for this interface is the discharge meeting occurring after specialist multidisciplinary assessment and care planning, and before the child or young person with ABI is to be discharged home or to another specialist setting. Involvement of Education Services at this time, in the form of a representative from the school the pupil is about to return to or be enrolled in, will help to facilitate comprehensive transfer of information from the clinical to the educational setting. If necessary, the representative could advise on educational procedures for securing appropriate support or alternative placement.

In cases where adult assistant support is attained, interventions and adjustments will only be as good as the knowledge and skills of the supervising teacher(s) or Special Educational Needs Co-ordinator (SENCo). There are very significant differences between children with a suddenly acquired and evolving pattern of cognitive and physical difficulties due to ABI compared to the more familiar and common presentation of children with congenital difficulties present since birth. Without this understanding, knowledge and skills gaps can occur

resulting in educational and psycho-social interventions being compromised. Schools can respond to this challenge by making a referral to the Child Brain Injury Trust or (in the case of a pupil with a Statement of Special Educational Needs) consulting with their Educational Psychologist.

Adult Community Brain Injury Teams (CBIT)

There are established Adult Community Brain Injury teams within each Trust which have traditionally only provided services to adults with ABI. With the exception of the specialist units there is little post discharge specialist service available to children with ABI. Services to children with ABI have traditionally been drawn from core children's services. In at least one Trust the particular expertise in respect of brain injury from an Adult CBIT has been accessed on a consultative basis in order to allow delivery of services to be retained by Trust children's services but the shaping and advice regarding such services has been facilitated by colleagues from the Adult CBIT. The pathway will ensure children's services will be co-ordinated to allow all the essential elements of care and rehabilitation to be provided to children and young people who suffered an ABI. Adult ABI community teams will work closely with colleagues in Children's Community Disability services in respect of children who have an ABI from the ages of 16 years to offer both a seamless transition to Adults Services and also to offer specialist advice on the management and support of ABI if this is required.

Community/Voluntary Sector

The role and contribution of community and voluntary sector providers is an important one. Agencies such as the Child Brain Injury Trust, the Cedar Foundation and other providers of services in respect of children with disability play a vital role in support services and advocacy. Post diagnosis services and support from the community and voluntary sector should be identified to parents and carers as soon as possible by the identified key worker. The services available should be included in the planning, review process and post initial assessment in terms of not only specific services but as advocates/supports for those with ABI and their carers.

Other Agencies

Agencies such as the PSNI and Youth Justice agencies have a significant role in working with young people and recent research undertaken by the University of Exeter has examined the links between youth offending and TBI and its relevance to those agencies and services working with offending and prevention of offending. Where these agencies have concerns regarding the existence of an ABI in young people they should initiate contact with the young person's GP or any health professional in contact with him/her in order to clarify

whether ABI is present and whether referral to the appropriate service is indicated.

Training

Staff should have specialist training and experience in working with ABI. Given the numbers who present in other settings each Trust should ensure that its multidisciplinary training needs analysis gives consideration to a range of training from awareness raising (Level I), focused (Level II) and more specialist (Level III) to ensure that sufficient skills are available in Trusts to provide the appropriate level of service. As a minimum staff should have awareness of ABI related assessments and outcome measures such as the paediatric FIM/FAM, GMFM and awareness of the use of treatments such as Botulinum toxin. Other important areas include staff who are trained in screening for new behavioural difficulties, anxiety and depression.

Data Collection

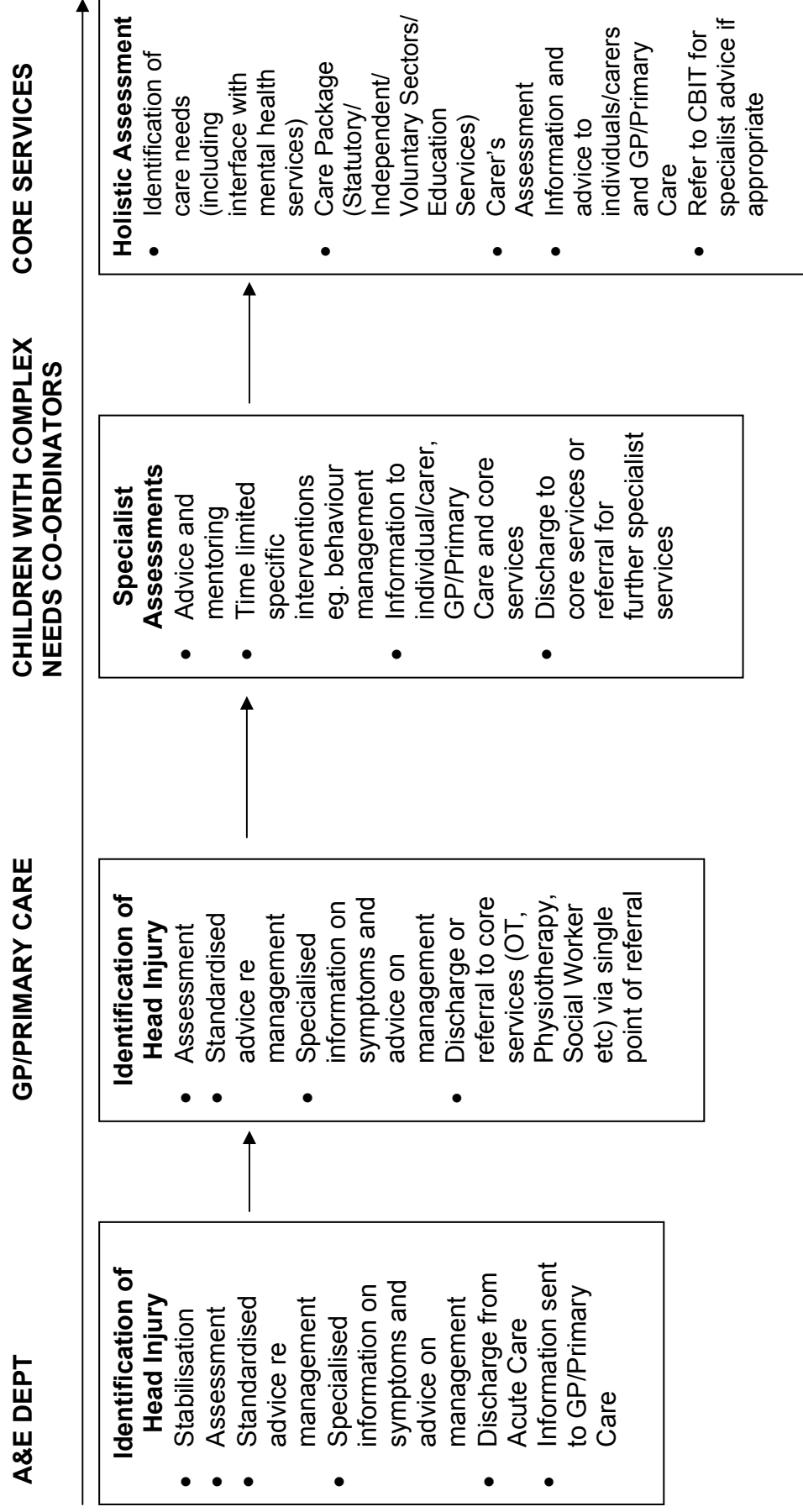
Each Trust should ensure that information is available regarding all children who present with head injury at any setting in terms of:

- Numbers
- Age
- Gender
- Outcome of initial contact
- If Service referred to and date
- If Service closed/date

2.4 Transition to Community Brain Injury Teams

The Health and Social Care Board has agreed to take forward a project looking at the issue of transitions between children and adult services for children with complex needs/disability. Whilst this project will be generic a specific protocol will need to be established between childrens services and adult CBITs/services. This should be agreed at a joint workshop with the adult workstreams of the Regional Acquired Brain Injury Implementation Group. Each Trust will have a policy in place for children with ABI transitioning to Adult Community Brain Injury Services.

3.0 Care Pathway – Mild to Moderate Acquired Brain Injury



3.1 Introduction

The presentation of a head injury may be described as mild to moderate in terms of clinical definition. However clinicians should be aware that the impact and outcome of what may be defined as mild to moderate may be significant in terms of the impact upon the young person and their carers. While this element of the pathways for ABI may relate to less serious clinical injuries all professionals should be aware and receptive to the needs and implications in broader terms on those children/young people who meet the criteria of mild to moderate ABI.

3.2 Presentation – Accident and Emergency, Minor Injuries Unit or GP Out of Hours Services

It will be assumed that most children/young people who have sustained minor injuries will present initially at local Accident & Emergency Departments, Minor Injuries Units or Out of Hours Services (OOH). Where a head injury has occurred or is suspected, the relevant clinical guidelines should be adhered to as recommended at the following: <http://www.nice.org.uk/nicemedia/live/11836/36259/36259.pdf>.

If admission is not required and the young person is discharged information should be provided to carers in respect of signs and symptoms of ABI. While this generally occurs at present the information provided is generally confined to what to do in relation to concerns in the immediate period post discharge. Information leaflets should now include information in relation to the longer term implications of what may appear as a minor injury and include advice on who to contact within the Trust. This may be the child's GP, Health Visitor or school nurse as appropriate to age.

On discharge the Accident & Emergency Unit, Minor Injuries Unit or Out of Hours Service should ensure that the notification of attendance and nature of attendance is communicated to the child or young person's GP. This should clearly state the reason for admission and if any investigations or concerns regarding head injury were noted.

3.3 GP/Primary Care Services

Where children or young people present to GP/Primary Care Services and where there is concern in relation to a head injury, the clinical decision to treat or to refer to secondary care will be the responsibility of the GP. Detailed records of the presentation or concern in relation to potential head injury should be retained in the file should indications of ABI present at a later date.

GP/Primary Care Services should be alert to changes in behaviour where patterns have changed and where attentional, memory and

speed of information processing difficulties are reported. In such cases the possibility that ABI is present should be considered.

3.4 Community Specialist Services

Given that the presentation of an ABI may mirror or be masked by other symptoms such as behavioural changes, social communication or personality changes all specialist community services such as ASD diagnostic clinics, ADHD clinics, CAMHS and behavioural therapy services, including Psychology, should ensure that a full clinical history is undertaken and consideration of the existence of an ABI noted.

Such services should also take cognisance that primary conditions such as gross motor delay, ASD, epilepsy and other conditions/ disabilities may lead to a predisposing risk of other injuries including head injuries. In all such cases awareness of this potential should be noted and interventions considered as appropriate to the individual case.

3.5 Core Services – Health and Social Care

There are a range of community services provided within Trusts to children and young people ranging from AHP provision, children's nursing services, multidisciplinary schools teams and social care services. All services should be aware that when undertaking initial assessments consideration is given to the awareness of ABI and in particular where there has been a change in behavioural patterns, learning and retention of new learning, and, any problems in relation to attention and concentration abilities. In such cases and with the appropriate consent, consultation with primary care providers including the child's/young person's GP should consider if ABI is a factor. In cases where there is a concern about potential implications from an ABI, referral to community paediatric services should be discussed and referral progressed.

3.6 Education Services

As with cases of moderate to severe injury, schools are the primary service in children's lives and thus will be hugely important in intervening and adjusting for potential cognitive and emotional/ behavioural needs of children with mild to moderate ABI. The challenge that such pupils pose for their respective schools continues to be significant but manifests somewhat differently from those with moderate to severe injury. Meeting the needs of these pupils also requires communication between medical and educational services however the focus is on notification that the child or young person has

suffered an ABI. Limitations of traditional cognitive assessment, the maturation of injury and teacher skill level are all complicating factors which influence the efficacy of resultant interventions.

The issue of identification is crucial. Where a child or young person has suffered a mild to moderate injury that did not result in a hospital admission it is important that the information is recorded at referral which can be accessed subsequently if required for multidisciplinary assessment and the information is recorded on file.

Although difficulties may not be evident initially, the latent effect of Brain Injury means that difficulties may only become evident at a later date when the neurological areas of damage are set to mature. Often if the cause of such difficulties (cognitive, emotional or social) is not correctly attributed then the interventions selected will be ineffective as they do not address the underlying need.

There are resultant implications for training teachers to work with this population as the more traditional methods of responding to need are often ineffective. The application of compensatory and by-pass strategies requires awareness of the neurological and psychological processes underlying learning. For many teachers initial guidance from specialists will be necessary. For pupils at Stage 1 and Stage 2 of the Code of Practice particularly, accessing this level of specialist knowledge and advice is ad hoc and may only be available through the voluntary sector from organisations such as the Child Brain Injury Trust. Only when a pupil proceeds to Stage 3 will their Educational Psychologist have access to inhouse specialist advice.

Moreover, it is important that assessment instruments are able to identify the deficits that are a hallmark of ABI. Children and young people with acquired attention, memory and speed of information processing difficulties can perform adequately on educational and psychometric tests which measure previous learning. This unrealistic picture may delay the pupil proceeding through the stages of the Code of Practice and accessing adequate support. Thus the gap between these children and their peers grows in the absence of early neuro-psychologically informed cognitive remediation.

Where cases are referred under the Code of Practice and where there is evidence of the emergence of significant cognitive and physical difficulties as outlined above, Educational Psychology services should consider the potential for ABI and should refer when appropriate to the relevant Trust Paediatric Services.

3.7 Other Agencies

Please refer to Page 13.

3.8 Community Specialist Provision for ABI Referrals/Advice

Agencies identified above who may need to make a referral for a child/young person with ABI presentations should be able to do so via a single point of entry through a lead community Paediatric Service.

4.0 Carers Assessments/Family Support

Family support is defined as the provision of a range of supports and services to ensure that all children and young people are given the opportunity to develop to their full potential. It aims to promote their development primarily by supporting and empowering families and strengthening communities. Its focus is on early intervention, ensuring that appropriate assistance is available to families at the earliest opportunity at all levels of need.

(Families Matter Strategy, DHSSPS, 2009)

Every child and family should have a multi-agency support plan agreed with them for the delivery of co-ordinated actions to meet their individual needs. This plan should be regularly reviewed. They should be facilitated to enjoy a good quality of life as a family (DHSSPS ICP CWCHN, 2009). This may take place as part of a UNOCINI assessment.

They should be enabled and supported to take part in decision-making through access to high quality information in easily accessible formats, taking account of communication abilities. Good quality information is an integral part of good quality healthcare. It can:

- Support the patient in making informed decisions
- Support and involve the family in the rehabilitation process
- Act as a reminder to the individual, family or carer of what they have been told
- Improve patient experience

Information (both verbal and written) should be offered and provided at various stages along the patient's journey. Information will be available in a variety of formats appropriate to the needs of the target population. Information about support networks, outreach services, self-help groups and community services is available.

Families will be allocated a named contact person who will co-ordinate the supports available to families. This role should be included in the person's job description and protected time allocated for this function. Each family will have a named 'core group' of professionals comprising those who have most contact with the child, such as teacher, therapist, social worker or nurse.

The support plan will be drawn up in conjunction with families and reflect their aspirations and needs for their child and for the family. Support elements should include:

- timely access to hospital and GP appointments.

- necessary adaptations, equipment and supplies are available to families on a timely and reliable basis.
- access to educational and leisure activities.
- carers informed about Direct Payments and assisted in making a decision about the appropriateness to them.
- opportunities provided for parents to have a break from caring.

A holistic and multi-agency approach will be used by community staff to record the outcomes of assessments, reports and reviews, thereby avoiding the need for multiple procedures and record forms. These records, which will include the assessment of the child's and family's needs, will be held by parents and should accompany the child into different settings/agencies thus avoiding parents having to repeat information. (NB: This may require a change to existing professional practice around record keeping).

The core group including the named contact will meet with parents as required to review service plans but at a minimum of every six months. Copies of these plans will be made available to families and all relevant service personnel. Parents will be able to request a review at any time. These reviews could be done in conjunction with other required reviews such as Looked After Children reviews.

Strategies for managing risks will be developed in conjunction with family carers and shared with all relevant personnel and agencies. These should balance safety with opportunities of ordinary living and be regularly reviewed.

The emotional well being of parents and siblings, and their quality of life is a major focus of reviews and the provision of advice and support. The inclusion of other services such as siblings support, carer's assessment or short breaks may require input from other professionals and the care planning process should facilitate this. It will be the responsibility of all professionals involved to ensure that the carers, including other carers such as young carers, needs are considered and that the appropriate offer of carers assessments in line with the core statutory duties upon Trust staff are progressed.

Adherence to existing pathway and assessment models such as UNOCINI should also be facilitated to ensure communication and review of information in respect of the child/young person and their carers needs.

5.0 Transitions

Every child/young person and family should have an agreed transfer plan, and no loss of needed services should be experienced as a result of the transfer. Planning for the transfer should commence around the young person's 14th birthday or earlier as required. Families need support and reassurance as they prepare for change and as they work through it. A link worker to assist the family in transition planning should be identified in community services to assist with the preparation for change. This worker should liaise with the relevant transition service from the Education and Library Board if involved.

Adult services in acute and community settings should be notified at this time about the pending transfer and appropriate staff invited to attend future planning meetings.

In the acute sector, a handover meeting should take place between the two specialists (children and adult) the young person and the family. Ideally one lead consultant will be named if there are two or more medical consultants involved with the child. Likewise a nurse from the children's ward will be identified to liaise with adult wards. The young person and family will be given the opportunity to familiarise themselves with the adult ward and nursing staff.

Ideally one named contact will be identified from adult services in the community. The named contact for the young person and family from children's services will convene a future planning group for the young person which will include representatives from adult services such as therapy, social work, day centre as anticipated. Prior to the transfer, they will meet at least annually to review the transition plan.

The group from health and social care will liaise with their counterparts in education to co-ordinate transition planning. One common Transition Plan will be prepared.

Clear lines of communication should be agreed between the family and adult community services; family and hospital; hospital and adult community services.

Trusts will anticipate the budgets that are required to provide continuity of service provision for assessed needs when the young person transfers from Children to Adult Services. The families will not be required to be placed on a waiting list for services that they continue to need.

Appendix I: National Service Framework for Children, Young People and Maternity Services (DH/DES, 2004)

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4090552.pdf

Standard 1: Promoting Health and Well Being, Identifying Needs and Intervening Early

The health and well being of all children and young people is promoted and delivered through a co-ordinated programme of action, including prevention and early intervention wherever possible, to ensure long term gain, led by the NHS in partnership with local authorities.

Standard 2: Supporting Parenting

Parents or carers are enabled to receive the information, services and support which will help them to care for their children and equip them with the skills they need to ensure that their children have optimum life chances and are healthy and safe.

Standard 3: Child, Young Person and Family-Centred Services

Children and young people and families receive high quality services which are co-ordinated around their individual and family needs and take account of their views.

Standard 4: Growing Up into Adulthood

All young people have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood.

Standard 5: Safeguarding and Promoting the Welfare of Children and Young People

All agencies work to prevent children suffering harm and to promote their welfare, provide them with the services they require to address their identified needs and safeguard children who are being or who are likely to be harmed.

Standard 6: Children and Young People who are Ill

All children and young people who are ill, or thought to be ill, or injured will have timely access to appropriate advice and to effective services which address their health, social, educational and emotional needs throughout the period of their illness.

Standard 7: Children and Young People in Hospital

Children and young people receive high quality, evidence-based hospital care, developed through clinical governance and delivered in appropriate settings.

Standard 8: Disabled Children and Young People and Those with Complex Health Needs

Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family-centred services

which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives.

Standard 9: The Mental Health and Psychological Well Being of Children and Young People

All children and young people, from birth to their eighteenth birthday, who have mental health problems and disorders have access to timely, integrated, high quality multidisciplinary mental health services to ensure effective assessment, treatment and support, for them, and their families.

Standard 10: Medicines for Children and Young People

Children, young people, their parents or carers, and health care professionals in all settings make decisions about medicines based on sound information about risk and benefit. They have access to safe and effective medicines that are prescribed on the basis of the best available evidence.

Standard 11: Maternity Services

Women have easy access to supportive, high quality maternity services, designed around their individual needs and those of their babies.

Appendix II: Positive Risk Taking

The Department of Health paper *Independence, Choice and Risk: A Guide to Best Practice in supported Decision Making (2007)* discusses the merits and difficulties of individual choices and decisions in the context of social care services and the risks that these may pose on the individual and others. The paper advises that the governing principle behind good approaches to choice and risk is that people have the right to live their lives to the full so long as that does not stop others from doing the same. It states that fear of supporting people to take reasonable risks in their daily lives can prevent them from doing the things most people take for granted and that what must be considered is the consequence of an action and the likelihood of any harm from it. However it argues that by taking account of the benefits in terms of independence, wellbeing and choice it should be possible for a person to have a support plan which enables them to manage identified risks and be able to live their lives in a way which best suits them:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_074775.pdf

Many of the individuals and families with disabled children consulted during the development of this strategy expressed the view that they wanted to live 'an ordinary life' with support and intervention provided as necessary from the various providers in terms of Health and Social Care, Education, transport etc. Nevertheless for those individuals who wish to pursue a more active or adventurous lifestyle this strategy supports such pursuits providing they comply with the governing principles as defined above.

Appendix III: Northern Ireland Family Support Model (Families Matter, DHSSPS, 2009)

The wider vision of family support has been articulated in the Northern Ireland Family Support Model, which has been adopted by the four Children and Young People's Committees in Northern Ireland. This wider vision of the totality of family support sets out how all organisations, with a responsibility for delivering services to children and families, should support families to become empowered, confident, responsible and able to help their children to reach their full potential. This strategy will be informed by this wider vision of family support, which sets a blueprint for all organisations across sectors and partnerships to enable children to achieve the outcomes set out in the children's strategy, through ensuring that a range of support services are developed for families and carers.

The Family Support Model, initially developed by Pauline Hardiker, is used to map and understand the range of family support services. It enables a 'whole system' approach to service planning to be conceptualised and emphasises the important links between the different levels of provision.

Furthermore, it is important that adequate service provision exists at all levels of the family support continuum. The most vulnerable children and families need to be supported in making the best use of the universal services that exist for all families. Many children and young people can be vulnerable at particular points of their development and will need the support of preventative services to ensure that more enduring problems are not allowed to occur.

Northern Ireland Family Support Model

It is important to recognise that populations of children with different needs are not mutually exclusive. This diagram starts with the total population of children and young people and smaller sub-populations with additional needs. This model details four levels of need, which can be responded to by four levels of services. The levels of services are described as follows:

Level 1: this represents services for the whole population, such as mainstream health care, education, leisure facilities, etc.


Level 2: this represents support for children who are vulnerable, through an assessment of need and are targeted through specific services.

Level 3: this represents support to families, or individual children and young people, where there are chronic or serious problems, provided through a complex mix of services across both the statutory and voluntary/community sector.

Level 4: this represents support to families, or individual children and young people, where the family has broken down temporarily or permanently.

It is widely acknowledged that early intervention produces positive dividends in terms of children and families not needing more specialist services at a later date. The aim of the higher levels of support (Levels 3 and 4) is to affect the situation in the family positively, so that the child and/or family can be supported through Level 1 and 2 services, (and therefore no longer need specialist services) alongside the mainstream population. This strategy, in conjunction with *Care Matters NI*, provides an integrated approach to ensure that needs based support is provided to all children and families, and that through investment in early intervention and prevention there will be a positive impact on families and a reduction in need for higher levels of support. Those responsible for planning and commissioning services are aware of the current inequity in resourcing early intervention services compared to those of higher needs and this must be addressed.


Utilising the Family Support Model will ensure good outcomes for children, young people and their families, service provision and service planning.



This Service Standards and Quality Indicators and Pathways pack was produced by the Health and Social Care Board's Regional Acquired Brain Injury Implementation Group in partnership with parents and carers.

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Please ask if you need this information in alternative formats: Large print, computer disk, Braille, audio tape or translation. Please contact the Health and Social Care Board on 028 2532 1206.

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Acquired Brain Injury Pathway for Children & Young People