



Department of
**Health, Social Services
and Public Safety**

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ACQUIRED BRAIN INJURY (ABI) ACTION PLAN

2008/09 – 2010/11

A CONSULTATION DOCUMENT

APRIL 2009

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MINISTERIAL FOREWORD

I am delighted to publish, for consultation, an Action Plan on Acquired Brain Injury (2008/2009 – 2010/2011). In doing so, my aim is to promote a person centred approach to earlier recognition, diagnosis, treatment, rehabilitation, care and support for individuals affected by acquired brain injury, their families and carers.

I recognise that the needs of individuals affected by acquired brain injury (ABI) will differ substantially, not just in relation to the nature and severity of their condition, but also their outcomes and goals. These will depend on the individual's physical, emotional, behavioural and cognitive impairment, their social and environmental circumstances, and their stage of life.

Regardless of age, all people with acquired brain injury should be supported to live as independently as is possible. This will require an integrated care planning approach that involves the individual, HSC staff, other agencies, and families and carers recognising their pivotal role in promoting the recovery of the affected individual.

The attached Action Plan draws much of its evidence from the *Review of Services for People with Acquired Traumatic Brain Injury in Northern Ireland*, which was commissioned by me in 2008. This Review found that whilst there has been significant development in ABI services in recent years, there is a sense of isolation of elements of the service – one from another – and an insufficient focus on strategic planning and management. In addition, there was little evidence of performance management information to inform service development.

Much has been done over the last 10-15 years to improve ABI service provision; however, more needs to happen. I am confident that by publishing this Action Plan, which will be implemented through a new Regional Acquired Brain Injury

Implementation Group, we can improve care and support for individuals, their families and carers.

New HSC structures will also assist, but it is through the valued commitment and determination of HSC staff, commissioners, voluntary and community sectors, and families and carers, that change will be achieved.

I am most grateful to Mr Richard Dixon and his team of experts for the production of the *Review of Services for People with Acquired Traumatic Brain Injury*. I believe that through publication of the attached Action Plan the issues raised in the Review will be addressed over time.

I strongly urge you all to respond to the consultation on the draft ABI Action Plan. The consultation ends on 12 May 2009.

Michael McGimpsey MLA
Minister for Health, Social Services and Public Safety

INTRODUCTION

1. This draft Action Plan for acquired brain injury builds on the Review of Services for People with Acquired Traumatic Brain Injury in Northern Ireland (September 2008).
2. This Review, which is available on www.dhsspsni.gov.uk, was commissioned by the Department of Health Social Services and Public Safety in response to concern raised regarding the treatment and care of people with traumatic brain injury. The Review's remit included the mapping of service provision, highlighting areas of good practice and identifying significant gaps in provision. Service provision was also considered in the context of equality and human rights. On the basis of its findings, the Review Team was asked to make recommendations to improve outcomes for people living with an acquired brain injury and their families and carers. The recommendations from the Review are contained in Appendix A.
3. Overall, the Review found that there was a sense of isolation of elements of the service and insufficient co-ordination of care for the commissioning and provision of services. In addition, there was little evidence of performance management information to inform commissioning or strategic planning. It was noted that there were particular issues regarding how the needs of children and older people with acquired traumatic brain injury were being addressed.

OUR AIM AND SCOPE OF THE ACTION PLAN

4. The purpose of producing this Action Plan on Acquired Brain Injury is to provide clear time-bounded goals to drive service improvement and to coordinate action in order to improve outcomes for patients (regardless of age), their families and carers. In this context acquired brain injury primarily, but not exclusively, relates to:
 - **Traumatic brain injury (TBI)** - injury resulting from trauma to the head and its direct consequences including hypoxia, hypotension, intracranial haemorrhage, raised intracranial pressure and gunshot wounds¹.

¹ Adapted from Multi-disciplinary rehabilitation from acquired brain injury in adults of working age (Review) – Turner-Stokes L, Disler PB, Nair A, Wade DT – *Cochrane Library 2008 issue 4*

However, it is recognised that there are other areas of acquired brain injury which overlap with traumatic brain injury. These include, for example:

- **diffuse acquired brain injury** - diffuse damage arising from trauma due to above, or a range of other acute incidents including hypoxia (e.g. due to drowning, electrocution, anaesthetic accident), hypoglycaemia, viral encephalitis;
 - **cerebrovascular accident (stroke)** - which may be ischaemic or haemorrhagic, and
 - **Other causes** - such as neurosurgical operations (e.g. removal of tumours), radiotherapy, cerebral abscess and meningitis)².
5. In the context of this Action Plan for Acquired Brain Injury, it is acknowledged that there will be some overlap of service commissioning and provision within the above categories. However, it should be stressed that the Action Plan relates to *stable patients in the post acute phase* of treatment, care and support for their particular condition. The Action Plan does **not** address the specific needs of patients with stroke, which are outlined in the DHSSPS Stroke Strategy – *Improving Stroke Services in Northern Ireland* (July 2008).
6. Patients with acquired brain injury experience a wide range of difficulties, depending on the nature, location and severity of their injury. For example, the brain injury may be mild, moderate or severe, with combinations of physical, communicative, cognitive, behavioural, psychosocial and environmental problems. Following the initial stages of recovery from the acute injury, the actual pathology of the underlying condition may not be as important as the post acute programme where the focus is on reduction of impairment and disability.
7. The outcomes and goals for individual patients will be very different, depending on their physical, emotional, behavioural and cognitive impairment, their social and environmental circumstances and stage of life. For example, the goals for a child with an acquired brain injury who has developmental, social and educational needs will be different to those of a young adult whose main focus may be a return to a working environment and parenting/family life. For older people who, for example, are retired, their goals are equally as important but will be different- their outcomes may relate to a return to family and social activities and retaining as much functional independence as is possible.

² Adapted from Multi-disciplinary rehabilitation from acquired brain injury in adults of working age (Review) – Turner-Stokes L, Disler PB, Nair A, Wade DT – *Cochrane Library 2008 issue 4*

8. This document, therefore, acknowledges that a **patient centred approach** is required for care planning, which takes account of the physical, social, communicative, cognitive, behavioural and environmental issues which may impact on the goals set for an individual patient. It takes account of in-patient, out-patient, and life-long care. In addition, there is clear need to involve families and carers in the care planning process, recognising their pivotal role in promoting recovery of the affected individual.

CURRENT SERVICE PROVISION

9. Current service provision for acquired brain injury in the post acute stage depends on the underlying cause of the condition, complexity, severity and age of individual (e.g. child, adolescent or adult), existing co-morbidities and other social and geographical factors. Early intervention and rehabilitation are key, with involvement of specialist teams appropriate to the needs of the individual. Composition of this team may vary, but could include medical and surgical professionals, nurses, allied health professionals, clinical psychologists, social workers and neuro psychiatrists and involvement of other agencies, for example, the voluntary sector, training, education, employers, housing and benefits agencies.
10. The *Review of Services for People with Acquired Traumatic Brain Injury* outlined details of the inpatient services provided by:
- Regional Acquired Brain Injury Unit (BHSCT -comprising 25 beds and outpatient services);
 - Maine Villa (BHSCT – Neuro Behavioural Unit - 15 beds, adult males with behavioural difficulties);
 - Thompson House (SEHSCT - 35 commissioned beds out of 40 – neurological disability, including acquired brain injury and complex conditions e.g. tracheostomy); and
 - Spruce House (WHSCT- Neurodisability Unit – 18 out of 24 beds commissioned).
11. Appendix B reproduces the table from the Review of Acquired Traumatic Brain Injury Report, which outlines the staff profile in each of the inpatient brain injury services.
12. In addition to above, some specialist services are commissioned from outside of Northern Ireland, for example, for female patients with extremely challenging behaviour and for children with complex needs. Boards currently fund these Out of Area Placements on a case by case basis (estimated at £1.39m in 07/08).

13. A GAIN³ audit is currently underway on the incidence of paediatric brain injury in Northern Ireland. This will be completed in June 2009 and will provide greater evidence of the extent of injury and follow-up care for children. The inpatient environment within the Belfast Trust for children with moderately severe acquired brain injury needs further detailed examination, including the provision of the inpatient environment, rehabilitation facilities and paediatric neurology follow-up.
14. All HSC Trust areas have adult community brain injury teams of varying compositions, admission and discharge criteria. Appendix C contains the Review of Traumatic Acquired Brain Injury Report staff profile and intervention statistics related to adult community brain injury teams. Based on the Reviews findings it is less clear how children with moderately severe brain injury requiring community based rehabilitation and follow-up, are managed within the community.
15. In addition to adult community acquired brain injury teams there are also community based teams for stroke rehabilitation in each Trust. It is unclear how the interface between these two teams of community-based services are managed. There are also a number of general physical disability rehabilitation teams to meet the needs of people of all ages with disability. Again the interface between these teams is not clear.
16. Community treatment and support has many additional dimensions including a variety of respite and domiciliary care arrangements, with involvement of the voluntary sector and other agencies providing supported living, day opportunities, social reintegration and pre/vocational rehabilitation, leisure activities and employment. These voluntary and private sector providers are essential in order to provide the breadth of options for patients, clients, carers and families.

DRIVING CHANGE – AN OVERVIEW OF THE ACTION PLAN

17. In driving change, it is recognised that the community and voluntary sectors have an important role to play, in addition to the statutory services delivered via other Departments such as Department of Education, Department of Employment and Learning, Department of Culture Arts and Leisure and Department of Social Development. This Action Plan acknowledges the pivotal role played by a range of agencies. However, our aim is to produce an action plan that promotes integrated working, recognising the pivotal place that Health and Social Care Services have in the prevention, protection, and improvement of health and social wellbeing. The Action Plan, therefore concentrates on:

Service Redesign- to include regional commissioning of ABI services and a virtual networked approach to the provision of flexible care at local level;

³ GAIN – Guidelines & Audit Implementation Network

Quality Improvement- to include a care pathways approach encompassing earlier recognition of patients with acquired brain injury, specialist inpatient care and rehabilitation, co-ordinated case management and community rehabilitation approaches to treatment, care and support. As part of development of the care pathway, there will need to be clear standards, referral criteria, and a common understanding of roles, responsibilities and linkages between The Regional Acquired Brain Injury Unit, local hospital services and community ABI Teams with due regard to best practice. The interface between the community ABI teams, stroke teams and general physical disability teams need to be clearly defined and it is recognised that the degree of similarity of approach within ABI and Stroke Teams may allow for pooling of resources. The care pathway for children will be different to that of adults but should encompass all the essential elements of care and rehabilitation.

Improved Support for Individuals, Carers and Families- support and therapy for carers should be provided recognising the very different needs of spouses, families and children, the importance of multidisciplinary working and the specific information and communication needs of individual patients, their families and carers.

Effective Engagement and Partnership Working- Effective communication, engagement and partnership working to provide a proactive case management approach, improve life opportunities for individuals, manage points of transition effectively, for example, from childhood to adulthood, and improve independence and social integration.

INTEGRATED CARE PATHWAYS

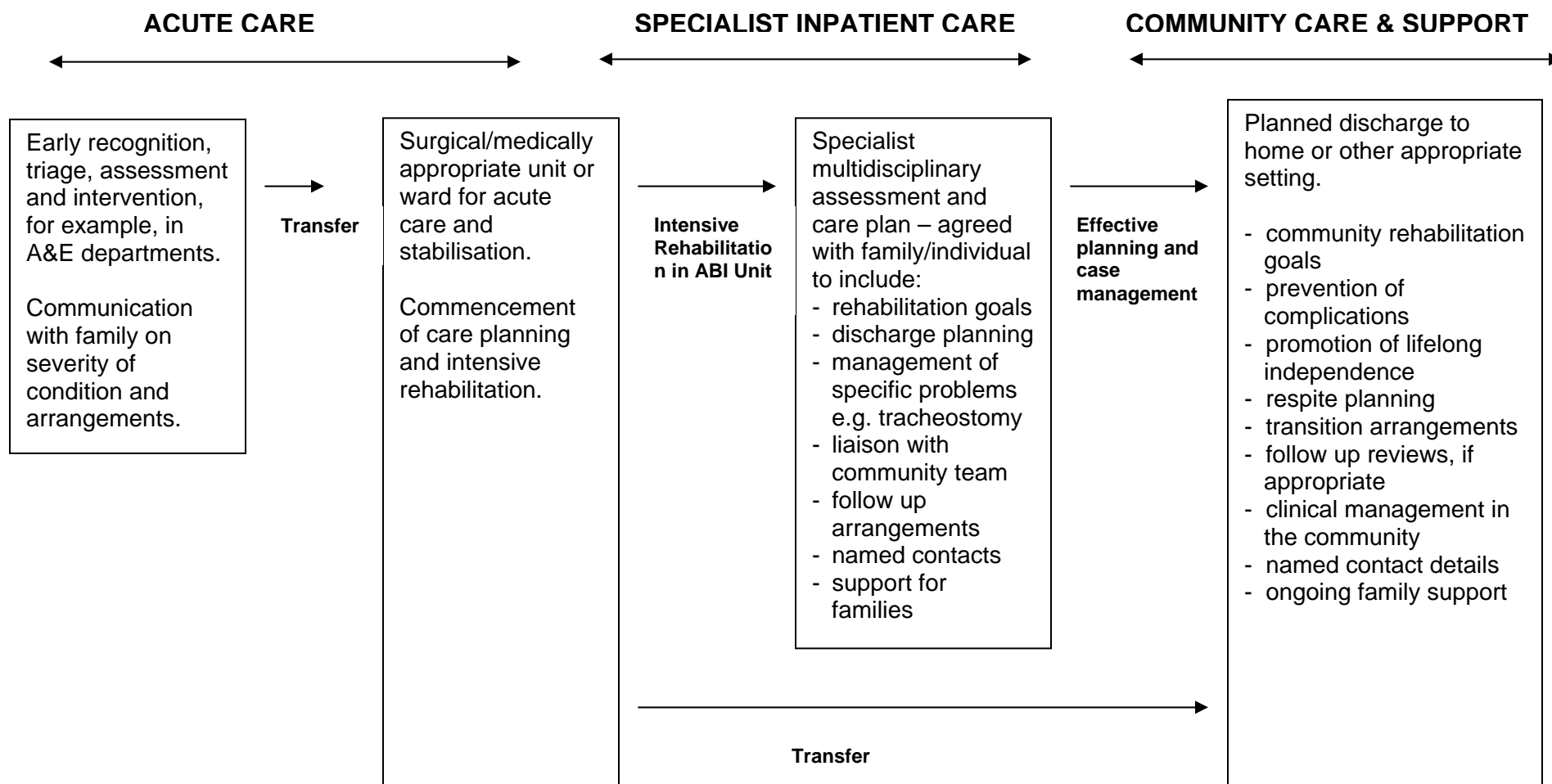
18. Figure 1 (page 11) aims to set out a generic care pathway for an individual with an acquired brain injury of a moderate to severe type. It is emphasised that a pathway of care for a child will be very different to that of an older person, as life opportunities and aspirations will vary greatly. Regardless of this, the care pathway should follow the same principles of:

- early recognition, acute intervention and stabilisation;
- ongoing communication and support for family;
- transfer to an appropriate unit or ward - post stabilisation of ABI;
- multi-disciplinary assessment, intensive specialist rehabilitation and integrated care planning;
- managed discharge and a proactive case management approach to community treatment and support;
- prevention of complications, promotion of life opportunities and independence, working with community, voluntary and private sectors, as appropriate.

19. Throughout the care pathway, a clear understanding of the respective roles and responsibilities of each unit or team needs to be agreed. Following multidisciplinary assessment, each patient should have a care plan, which is shared with and agreed by the individual and/or their family. Standards of care need to be documented at the different stages of the care pathway. These standards should be informed by evidence based practice, the standardisation of data collection systems and the use of quantitative and qualitative data to drive performance improvement.
20. Ongoing training, education and leadership are essential to maintain a focus on service redesign and improvement in ABI services. To this end this Action Plan will be co-ordinated through a new Regional ABI Implementation Group, which will inform the regional and local commissioning of ABI services and will drive performance improvement. This Regional ABI Group will be accountable to the new Health and Social Care Board. It will promote a networked approach to specialist inpatient provision and consistency of approach, where appropriate, to community service provision.

Figure 1

INTEGRATED CARE PATHWAY FOR ACQUIRED BRAIN INJURY (moderate to severe ABI condition)



RESOURCES

21. From 2009/2010 to 2011/2012 an additional £1.2m cumulatively will be invested in acquired brain injury services producing £0.7m recurrent funding in 2010/2011.
22. The Action Plan will inform service development and resource allocation. However, whilst it is recognised that the Action Plan primarily relates to the 2008/2009 – 2010/2011 period, further investment will be needed to achieve all objectives.
23. Opportunities should be sought to explore the potential to redirect funding from Out of Area Placements (estimated at £1.39m in 07/08).

OUR PRIORITIES

24. Additional financial resources, as identified above, represent a welcome starting position; however, much can be done to reorganise ABI services now, which is not contingent on substantial additional investment.
25. Our priorities are influenced by the need to improve and co-ordinate service development. These are:
 - i. Promote leadership to effect change with a clear programme of work to be delivered by the Regional Acquired Brain Injury Implementation Group, which will be accountable to the HSC Board;
 - ii. Promote regional commissioning of ABI services, and coordinated service delivery through a virtual ABI networked approach;
 - iii. Standardise the care pathway – to promote equity of access by development of agreed referral criteria, standards and protocols;
 - iv. Implementation of individualised care plans, with clear rehabilitation goals and an active approach to discharge planning;
 - v. Promote early identification of patients with acquired brain injury and linkages between general hospital wards and the acquired brain injury network;
 - vi. Clearly define roles, responsibilities and linkages and future strategic direction of each component of the virtual ABI network to include:

- Regional Acquired Brain Injury Unit (BHSCT);
 - Thompson House (SEHSCT);
 - Maine Villa (BHSCT);
 - Spruce House (WHSCT); and
 - Local community brain injury teams and other service providers.
- vii. Implement Priorities for Action target for 2009/2010 to ensure a 13-week maximum waiting time from referral to assessment and commencement of specialised treatment;
 - viii. Clearly define the roles and responsibilities of community acquired brain injury teams and interfaces with specialist inpatient teams and other related teams, for example, stroke teams and general disability services;
 - viii. Identify the incidence of acquired brain injury in children, and in older people, in order to plan effectively for future service provision;
 - ix. Place a particular emphasis on quality improvement and performance management with the development of quality indicators, which recognise the importance of good clinical care, patient and family experiences, value for money and the benchmarking of performance against other specialist units;
 - x. Recognise the importance of family support along the care pathway and the importance of promoting independence and ongoing support for individuals and their carers; and
 - xi. Support education and training of staff and enhanced information to those who care for individuals with acquired brain injury.

NEXT STEPS

26. Appendix D contains the Terms of Reference of the Regional ABI Implementation Group. The Regional ABI Implementation Group will commence its work from April 2009. The work of the Regional Group will also be linked to the Service Delivery Directorate of the new Health and Social Care Board.
27. Through the new Health and Social Care Board, the Department will expect a progress report on actions on a six monthly basis with formal review of this Action Plan in 2011.

HOW TO RESPOND

28. This draft Action Plan is being published for consultation on 31 March 2009.

29. Everyone with an interest in improving acquired brain injury services is invited to respond. This can be achieved by completion of the attached questionnaire.

30. Responses to the consultation can be sent by post to:

Colin Dunlop
Physical and Sensory Disability Unit
Room D2.1
Castle Buildings
Stormont
BELFAST BT4 3SQ
Tel: 028 90 520766

Or by e-mail to: colin.dunlop@dhsspsni.gov.uk

Responses must be received no later than 12 May 2009.

31. The consultation document is being circulated to key interest groups – Health and Social Care Services and other Government Departments. Additional copies are available on www.dhsspsni.gov.uk/index/consultations.htm.

Acquired Brain Injury

Draft Action Plan

2008/09 – 2010/11

Key Themes

- S** = Service Redesign (supporting people to achieve their full potential through enhanced service commissioning and provision)
- Q** = Quality Improvement and Performance Management
- I** = Improved Support for Individuals, Carers and Families
- E** = Effective Engagement and Partnership Working

Theme: Service Resign (S)

ABI Action Plan Ref Nos	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
S - 1	<p>Establishment of Regional Acquired Brain Injury Implementation Group</p> <p>Create a regional multi-disciplinary, multi-agency Regional Acquired Brain Injury co-ordination and implementation infrastructure accountable to the HSC Board, working in collaboration with other agencies and services.</p>	<p>DHSSPS</p> <p>RHSCB from April 2009</p>	<p>Formation of Regional HSC Board (from April 2009).</p>	<p>Commencement end March 2009</p> <p>End May 2009-Sub-groups as required:</p> <ul style="list-style-type: none"> - care pathways; - standards; - development of family support; - training and education. 	<p>The early commencement of an integrated Regional Acquired Brain Injury Implementation Group will ensure that the structure is in place.</p> <p>The Group will provide a forum for interdisciplinary, multi-agency working.</p>
S - 2	<p>Development of a regional commissioning framework which includes:</p> <ul style="list-style-type: none"> - specialist inpatient services; - community/outpatient services; <p>to encompass all age groups.</p> <p>ABI services should be regionally commissioned and delivered through a virtual networked approach incorporating specialist services and community teams.</p> <p>The virtual specialist network should include:</p> <ul style="list-style-type: none"> - RABIU - Thompson House - Spruce House - Maine Villa - Community Brain Injury Teams and Services 	<p>HSC Board Local Commissioning Groups HSC Trusts Community and Voluntary Sector</p> <p>HSC Board RABIU HSC Trusts Community and Voluntary Sector</p>	<p>Uniformity of approach in the commissioning of care for people with acquired brain injury, to improve services and outcomes.</p> <p>Integrated service delivery.</p>	<p>March 2010</p> <p>March 2010</p>	<p>To standardise care across the acquired brain injury service, this needs to be regionally commissioned to agreed standards and delivered through a specialist virtual network approach, linked to community brain injury teams</p> <p>Coordinated care planning approach and integrated delivery of services.</p>

ABI Action Plan Ref Nos	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
<p>S – 3</p> <p>S –3 (a)</p> <p>S –3 (b)</p>	<p>Detailed service mapping for adults and children services:</p> <p>Identify service components and gaps in Trust specialist teams, to build specialist inpatient services based on assessed need and available resources.</p> <p>Detailed service map of acquired brain injury community teams with particular reference to adults and interfaces with children’s services, stroke services and the linkage with inpatient specialist services.</p>	<p>Regional Acquired Brain Injury Implementation Group HSCB (from 1 April 2009) HSC Trusts</p>	<p>Improved understanding of current service provision for:</p> <ul style="list-style-type: none"> - inpatient services, - outpatient/ community services; and - life long support. 	<p>Baseline current service provision by end August 2009.</p> <p>Identification of key components, and workforce requirements – October 2009.</p> <p>Enhanced teams in place by August 2010.</p>	<p>Following mapping of current service provision, there will be further development of specialist teams at local level, to deliver earlier recognition, assessment, treatment and care to agreed standards and development of a clear care pathway for children, adults and older people.</p>
<p>S –3 (c)</p>	<p>Identify incidence of ABI in children, and in older people.</p>	<p>Regional Acquired Brain Injury Implementation Group RABIU, GAIN Paediatric Neurology Services, HSC Trusts</p>	<p>To ensure the service configuration best meets the needs of these groups.</p>	<p>Children – July 2009</p> <p>Older people – December 2009</p>	<p>Children’s rehabilitation at inpatient level and within the community requires a detailed assessment of need to ensure appropriate linkages with other specialist rehabilitation and education services are delivered.</p> <p>The needs of older people who have an acquired brain injury will require quantification and a clear pathway on where best these needs are met especially to provide coordinated rehabilitation with the development of community brain injury services that complement existing stroke and dementia services.</p>
<p>S – 4</p>	<p>Standardise the care pathway</p> <p>Standardise care pathways across Northern Ireland taking account of local, national and international examples of established best practice, the needs of children, adults and older people.</p>	<p>Regional Acquired Brain Injury Implementation Group Primary Care HSC Trusts Other sectors</p>	<p>Improve understanding and integration of the care pathway approach to be used by the specialist inpatient ABI services and community brain injury teams. Standardised care pathways and</p>	<p>March 2010</p>	<p>Clear understanding of the pathway of care, including inpatient care, outpatient care, lifelong care and discharge planning, and the specialisms that a service user, family or carer can expect to use (e.g. RABIU, Community Brain Injury Teams, Community Rehabilitation Teams, Stroke Units, Speech &</p>

ABI Action Plan Ref Nos	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
			<p>agreed referral protocols for initial assessment and information provided to specialist teams</p> <p>Agree integrated care pathway for children, adolescents and all adults with suspected Acquired Brain Injury.</p>		<p>Language Therapy etc.) to facilitate an individual to maximise their function and potential.</p>
S – 4 (a)	<p>Develop agreed service standards for referral, access, assessment, diagnosis, intervention along the care pathway for both children's services and adult services taking account of the specific needs of older people.</p>	<p>Regional Acquired Brain Injury Implementation Group</p> <ul style="list-style-type: none"> - HSC Trusts - Primary Care 	<p>Development of clear service standards along the care pathway for earlier recognition, assessment, diagnosis and interventions within HSC services.</p>	<p>March 2010</p>	<p>Agreed regional service standards across the network. The benefits are to improve treatment, care and support for inpatients, outpatients and lifelong care, and to inform a regional commissioning framework.</p>
S – 4 (b)	<p>Adoption by all HSC Trusts and Primary Care of standardised referral processes / protocols across Northern Ireland for cases where there is a suspicion of Acquired Brain Injury.</p>	<p>Regional Acquired Brain Injury Implementation Group, HSC Trusts in collaboration with LCGs and primary care.</p>	<p>Standardised referral pathway to include agreed information requirements.</p>	<p>31 December 2009</p>	<p>Streaming information makes specialist assessment easier and assists in monitoring of waiting times.</p>
S – 4 (c)	<p>Clarify remit and harmonise services within community brain injury teams taking into account existing best practice.</p> <p>Develop clear protocols on the interface between community brain injury teams, community stroke teams, and the specific needs of childhood rehabilitation services.</p> <p>Ensure harmonisation of referral protocols to community brain injury</p>	<p>Regional Acquired Brain Injury Implementation Group, HSC Trusts in collaboration with Primary Care.</p>	<p>Harmonisation of development of community brain injury teams to agreed protocols, recognising the need for local flexibility in delivery.</p>	<p>December 2009</p> <p>December 2009</p> <p>December 2009</p>	<p>A clearer understanding of the services provided by community brain injury teams as part of a virtual network approach. Referral criteria need to be clear in order to improve performance and standardise the care pathway.</p>

ABI Action Plan Ref Nos	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
	teams taking into consideration the diverse referral sources.				
S –4 (d)	Development and introduction of protocols to allow more effective identification of acquired/traumatic brain injury on presentation to acute services.	Regional Acquired Brain Injury Implementation Group, HSC Trusts in collaboration with Primary Care and LCGs.	Earlier recognition of: <ul style="list-style-type: none"> - mild brain injury and improved information for patients, carers and family; - moderate – severe brain injury; will improve outcomes.	June 2010	Patients who present, for example to A&E Departments, with mild brain injury need standardised information. Earlier recognition of moderate to severe brain injury, regardless of the age of the individual has the potential to improve outcomes.
S – 5	<p>Promoting a care planning approach</p> <p>For moderate to severe brain injury, a care plan should be available for each patient - from initial concern of Acquired Brain Injury and/or point of referral to cover the period between suspected/provisional diagnosis of Acquired Brain Injury and receipt of specialist services and interventions to facilitated discharge and lifelong care.</p> <p>The care plan should be developed in collaboration with the family and carers.</p>	Brain Injury Implementation Group, HSC Trusts in collaboration with other partners.	<p>Individual care plans available to families to provide initial advice and support between provisional diagnosis and the receipt of specialist Acquired Brain Injury services.</p> <p>A named key worker from the MDT to provide family support at each key stage, recognising the need for partnership working with other agencies, and resource constraints in the system.</p>	31 March 2010	<p>For moderate/severe cases, there should be clear care plan which is developed early on to meet the needs of individual patients, carers and families. It should support through initial stages of referral and assessment, provisional diagnosis, especially for complex cases.</p> <p>This should be available regardless of the age of presentation of Acquired Brain Injury.</p>
S – 5 (a)	Development of community care options and appropriate placements for people who are minimally responsive and in persistent vegetative states, including those with ABI who also have a tracheotomy,	Regional ABI Group HSC Board HSC Trusts Community, Voluntary and Private Sector	Regionally commissioned services needs to include a focus on lifelong care for those who have severe ABI to include a	March 2010 – ongoing	Incorporate lifelong care into the regional commissioned process which reinforces the commitment to person-centred care.

ABI Action Plan Ref Nos	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
	taking account of the care needs of the individual and family. These options should be developed in a number of localities (at least one in each Trust area) to facilitate families who may be visiting over many years.		<p>recognition of the need for individually care management packages and agreed standards for tracheotomy care.</p> <p>Effective management / pathway to achieve decannulation.</p> <p>Tailored care plan for patient and family.</p> <p>These options should be developed in a number of localities.</p>		Where deemed appropriate, provide the option of community based care and rehabilitation.
S – 6	<p>Regular reviews of Extra Contractual Referrals for those with Acquired Brain Injury</p> <p>Carry out a needs assessment to explore options for local service development.</p>	Regional ABI Implementation Group HSC Trusts	Individual care reviews are undertaken to facilitate planning of a graduated pathway for return, if appropriate.	April 2009 onwards	Facilitate for return of individuals from UK/Rol to enable patients to be geographically closer to family members.
S – 7 S – 7 (a)	<p>Improve access to specialist inpatient provision</p> <p>Review and recommend actions for the provision of a region-wide comprehensive in-reach service from the Regional Acquired Brain Injury Unit into acute and general inpatient wards.</p>	Regional ABI Group Belfast HSC Trust Regional Acquired Brain Injury Unit	<p>Leadership & specialist input from RABIU across the virtual specialist network to include</p> <ul style="list-style-type: none"> ; - Thompson House - Spruce House - Maine Villa <p>And general inpatient wards</p>	December 2009	<p>Using a virtual network approach:</p> <p>To ensure agreement and facilitation of access to specialist opinion; and</p> <p>Promote access to appropriate specialist services subsequent to that opinion.</p>

ABI Action Plan Ref Nos	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
S – 7 (b)	Where second opinion is required, improve access through assistive technologies, linking to international specialist centres if required.	Regional implementation network HSC Board RABIU	To improve outcomes for a minority of complex cases, a specialist opinion may be required.	Linkage to ICT Strategy on assistive technologies	As ICT links improve, for very specialist cases, a second opinion may be required through assistive technology, using, for example, video conferencing techniques.
S – 7 (c)	Further development of Spruce House to enable it to become a regional inpatient and outpatient facility.	HSC Board/WHSSB Western HSCT	Spruce House to be part of a network of ABI services, providing inpatient specialist care and co-ordinated outpatient care.	December 2009	All units to be part of a specialist ABI network with a clear understanding of specialist inpatient facilities and outpatient care to agreed standards of the network.
S - 7 (d)	Secure additional input from a Consultant in Rehabilitation Medicine at Thompson House and Spruce House via the virtual ABI network. Development of specialist teams appropriate to inpatient care to include medical, AHP, nursing, social care neuropsychology and, neuro psychiatry.	Regional ABI Group RHSC Board RABIU South Eastern HSCT Belfast HSCT Western HSCT	Improved rehabilitation and outcomes through the development of specialist inpatient rehabilitation teams.	December 2009	Expert input into the care planning process is required to ensure effective rehabilitation, and where appropriate discharge planning.
S – 8	Improved inpatient facilities Provision of suitable inpatient accommodation for adults with neuro behavioural disorders at a regional and local level.	HSC Board Belfast HSCT Regional Implementation Group	Improve environment for those currently residing in Maine Villa to enable those with neuro behavioural disorders to receive improved treatment and care and to deliver a stepped care approach allowing long-term patients to be cared for locally. Explore possibility of relocation – to accommodate an	December 2009 March 2010	Better outcomes for adults with neuro behavioural disorders. Better outcomes for adults with neuro behavioural disorders.

ABI Action Plan Ref Nos	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
	Provision of brain injury beds, in an appropriate environment, for children with acquired traumatic brain injury.	Belfast HSC Trust HSC Board DHSSPS	integrated approach to the management of neuro disability, including neuro behavioural disorders. Improved environment for children with moderate/severe brain injury – commitment to include in future Women's and Children's Hospital Plan.	2011 onwards	Improve inpatient provision for children with ABI as part of development of new Women's and Children's hospital facilities.
S – 9	Development of a range of locally based supported living, residential nursing care options, and floating support, including services for those people with challenging behaviours.	Regional Acquired Brain Injury Implementation Group Vocational/private sectors. Department for Social Development NI Housing Executive	Promotion of independence and lifelong care and support for individuals, families and carers.	2009-2011 and ongoing	An individualised care plan needs to include discharge arrangements appropriate to the needs of the individual in order to maximise independence and ongoing support.

Theme: Quality Improvement and Performance Management (Q)

ABI Action Plan Ref Nos	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
Q – 1	<p>Development of Quality Indicators for the performance of Community Brain Injury Teams.</p>	<p>Regional Acquired Brain Injury Implementation Group</p> <p>HSC Trusts</p> <p>Service Delivery Directorate – HSC Board</p>	<p>Standardised Quality Indicators adopted for use by all Community Brain Injury.</p>	<p>March 2010</p>	<p>Measurement of standards through an agreed set of quality indicators – will harmonise care and drive performance improvement.</p>
Q – 2	<p>Benchmarking of the Regional Acquired Brain Injury Unit against specialist centres in the UK or internationally, with establishment of quality indicators for the unit.</p> <p>Establishment of a regional performance management improvement system with specific acquired brain injury quality indicators taking account of standards developed.</p>	<p>Regional Acquired Brain Injury Implementation Group.</p> <p>HSC Trusts to lead in collaboration with Service Delivery Unit.</p>	<p>Development of a small number of measurable performance indicators covering:</p> <ul style="list-style-type: none"> - recognised standards of care; - service user and carer satisfaction; and - value for money. 	<p>March 2010</p>	<p>Performance indicators will drive improvement and will contribute to the documentation of these improvements at HSC Trust and regional level.</p>

Theme: Improved Support for Individuals, Carers and Families (I)

ABI Action Plan Ref Nos	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
I – 1	Provision of appropriate information for people with mild brain injury, moderate to severe brain injury and their families and carers	Regional Acquired Brain Injury Implementation Group Voluntary, Community, Private Sector and other Government Departments	Standardisation of communication and information for patients, families and carers with regard to mild/moderate and severe brain injury.	September 2010	Will help to address the needs of family members and carers during patient rehabilitation. Signposting to support and other services e.g. counselling/psychological therapies.
I – 2	Development of range of age-appropriate respite options for people with an acquired brain injury who are living with carers	Regional ABI Group HSS Trusts Voluntary/Private Sectors Other agencies	Enhance the range of respite care appropriate to the needs of individuals e.g. – day opportunities, adult placement services, leisure activities, family support.	2009-2011 and ongoing	The Regional ABI Group in collaboration with the voluntary/private sector and other agencies should give due attention to the development of respite opportunities across the ABI network.
I – 3	Improve communication with families and carers	HSC Trusts Regional Implementation Group	A nominated lead worker should be included within the care plan to liaise with the patient and their family.	March 2010	Provision of necessary information for the ongoing care and support of the individual, their family and carers.
I - 4	Involvement of patients and carers in service planning, commissioning, delivery and evaluation of acquired brain injury services	HSC Trusts Regional ABI Group	Evidence of service user, family and carers involvement in HSC planning, commissioning, delivery and evaluation of ABI	December 2009 ongoing	The ABI Implementation Group should determine how best service users and carers' views are incorporated in to their work.

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Service Delivery Unit

services.

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HSC Trusts and HSC Board should involve users and carers in planning, commissioning and service development.

Theme: Effective Engagement and Partnership Working (E)

ABI Action Plan Ref Nos	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
E-1 E-1 (a)	Effective engagement and partnership working Promote effective working and the sharing of information and best practice with other sectors and agencies.	Regional ABI Group Voluntary/Private sectors Other agencies	Access to, and engagement with interested parties, to take forward the Acquired Brain Injury Action Plan. Outcomes to complement other Government Action Plans.	Ongoing	This action is intended to enhance integration and to share information and best practice in the interests of providing appropriate Acquired Brain Injury services to individuals and their families.
E-1 (c)	Horizon scanning on ABI service development and innovation, to inform future commissioning and resource allocation.	Regional ABI implementation group HSC Board	Service development should be premised on evidence based practice. Co-ordination of evidence base to inform future resource allocation is essential.	2009-2010 and onwards	Feedback to the Department and HSC Board on evidence based service developments is essential for the continued development of an effective ABI service.
E-2 (a)	An education and training plan should be developed for future service development as part of the networked ABI approach.	Regional ABI Implementation Group RABIU	Implementation of evidence base standards of care and workforce development, through co-ordination of an agreed education and training plan.	2010 onwards	RABIU as part of the ABI networked approach should lead on the development of an education and training plan to complement agreed standards of care, both for specialist inpatient services and community care.

RECOMMENDATIONS OF THE REVIEW**Commissioning**

1. A regional managed clinical network for acquired traumatic brain injury (ATBI) should be established with appropriate authority, resources and strategic direction.
2. Needs assessment of older people and children with acquired traumatic brain injury should be undertaken.
3. The commissioning process should recognise quality of life issues, and prioritise services for this, alongside vocational and similar objectives-based programmes. This is likely to require involvement of other agencies in addition to Health and Social Services.
4. Every effort should be made to allow people recovering from ATBI to receive their treatment and care as close to home as possible. In particular, the alternatives to the referral of patients overseas should be explored as a matter of priority.
5. A comprehensive family support service should be commissioned to address the needs of family members and carers at all stages of the rehabilitation process.

Inpatient and outpatient Services

1. Comprehensive rehabilitation care pathways should be created for children, adults and for older people with a common co-ordinating lead, ensuring equity of access and timely onward acceptance of patients as they progress through the continuum of rehabilitation.
2. Protocols should be introduced to identify and assess people with ATBI on presentation to acute services, and to notify them to brain injury service providers.
3. The Regional Acquired Brain Injury Unit should be developed as a resource for training, education and research in brain injury.
4. Appropriate environments should be provided within acute hospitals for people with brain injury, taking account of their specific needs.
5. Consideration should be given to replicating the role of a nurse linked with brain injury specialist services, to identify and facilitate the pathway for brain injured people on acute and general inpatient wards (as already established by the Northern Trust).
6. As part of service redesign, the current under-utilisation of Spruce House should be addressed. It should be developed as a key sub-regional inpatient and outpatient facility for rehabilitation of people with brain injury following discharge from acute services and RABIU.
7. Additional input by a Consultant in Rehabilitation Medicine should be provided to services at Thompson House Hospital and at Spruce House, Altnagelvin Hospital, taking due regard of current national guidelines (i.e. 1 Consultant per 250,000 population).

8. Alternative accommodation should be developed for the regional inpatient service for people with challenging behaviour to allow for the admission of women and for an improvement of the environment in which this care is provided. Neuropsychiatric provision and support should be enhanced across the ATBI network to provide for this.
9. Appropriate accommodation should be provided for children with brain injury receiving inpatient rehabilitation as part of the development of the new hospital for Women and Children in Belfast.
10. Clinical and professional staff resources should be provided appropriate to meet the inpatient rehabilitation needs of children.

Community

1. Community Brain Injury Teams in each Trust area should be maintained and staff profiles streamlined to secure equity of access to services provided by such teams.
2. A community-based regional service should be established to address the rehabilitation needs of children, appropriately linked to inpatient and outpatient children's rehabilitation services and to the wider network of brain injury services.
3. The development of supported living and residential options should be sponsored for people with challenging behaviours following brain injury who have completed their programme of rehabilitation.
4. Nursing home places should be developed for people who are in minimally responsive and persistent vegetative states – including those with a tracheostomy who have completed their programme of rehabilitation.
5. The development of age-appropriate respite for people with brain injury living with carers should be supported.

Voluntary sector

1. Existing services for pre-vocational and vocational rehabilitation and for social re-integration should be maintained.
2. Services for people with brain injury that are social in their nature and benefits should be strengthened, alongside goal-directed training and similar provision.
3. A forum for service users and carers should be developed, to participate in the ongoing development of brain injury services generally.

STAFFING PROFILE- ADULT INPATIENT BRAIN INJURY SERVICES
August 2008

Staff Profile by Grade and w.t.e.	Belfast Trust		South Eastern Trust	Western Trust
	RABIU (25 beds and OP)	Maine Villa Knockbracken (15 beds)	THH, Lisburn (35 beds out of 40 in use)	Spruce House (18 beds out of 24 in use)
Rehabilitation Service Manager	0.15		0.33	
Asst Service Manager	0.15			
Consultant Rehab Medicine	2.0			
Consultant Neuro- Psychiatry	0.2	0.3		
Staff Grade	1.0			
Consultant Neurology			0.1	0.1
Specialist Registrar	1.0	0.2		
SHO				
General Practitioner		0.3	0.5	0.3
Nurse manager 7	1.0	1.0	1.0	1.0
Senior Nurse 6	2.0		3.0	2.0
Staff Nurse 5	25.80	14.62	21	12.67
Nursing Asst 3	9.0	2.0		
Nursing Asst 2	10.55	9.95	19.39	8.54
Neuropsychology consultant	1.0	0.1	0.2	
Psychology Consultant				
Psychology Principal	2.0	0.5	0.4	
Psychology Asst.				
Social Work Senior.				
Social Worker	2.0	0.5	0.5	
Dietician	2.0			
Physiotherapy Rehabilitation Asst	2.0			
Rehabilitation Asst				
Art /Activities Therapist	0.5		1.35	
Music Therapist	0.5*			
Physiotherapist 8	1.6			
Physiotherapist 6	8.0		1.2	1.3
Physiotherapist 5	2.0			
Occupational therapist 7	1.0			
Occupational therapist 6	4.0	0.5	0.5	0.5
Occupational therapist 5	6.0			
Occupational therapy Asst 2/3	4.0			
Speech & language Therapist 8	2.75		0.3	
Speech & language Therapist 5	2.0			
Speech & Language Therapy Assistant 3	1.0			
Total Staff	95.20 w.t.e.	29.97 w.t.e.	49.77 w.t.e.	26.41w.t.e

*0.5 WTE Music Therapy funding bought on sessional basis from NI Music Therapy Trust

**Staff profile and intervention statistics, Adult Community Brain Injury Teams
August 2008**

STAFF Profile by Grade and w.t.e.	N&W BHSCT	S&E BHSC T	Mourne BHSCT	Total	NHSCT	SHSCT	SEHSCT (2 teams)	WHSCT
Team Coordinator/ Lead (Neuropsychology)	0.5	0.1	0.1	0.7				
Rehabilitation Manager							0.33	
Rehabilitation Consultant					0.1	0.1		
Neuro-Psychiatry	Liaison as required						1 session monthly	
Neuro Psychologist Consultant					1.00			
Neuro Psychologist	0.5	0.1	0.1	0.7	1.00		0.8	
Clinical Psychologist		0.5		0.5	1.00	1.00	1.35	1.00
Psychology Asst		1.0	1.0	2.0	1.00		0.8	
Speech and Language Therapist	0.5	0.3**		0.8	0.91	0.55	0.7	
Occupational Therapist	1.00	1.3	0.2	2.5*	1.0	1.0	1.4	2.5
Physiotherapist	0.5			0.5	1.3	0.55	0.5	0.5
Rehabilitation Nurse					1.00		0.8	
Social Worker	0.5	1.0		1.5	1.00	1.0	1.50	3.00
Rehabilitation Assistant/ Support Wkr /Floating Support	1.0			1.0	4.50		1.8	3.6
Day Rehabilitation Manager			1.0	1.0	1.00			
Day Care Workers			3.0	3.0				
TOTAL STAFF WTE	4.5	4.3	5.4	14.2	14.81	4.20	9.98	10.6
Average active case load 07/08					138 M 45 F	120 open/active	76 open/ 75 review	89
Average length of service					No time limitation	1196 days Including L/T clients	215 days 175 days	182 days

**0.3 wte SLT – vacant *2.0 wte OT - vacant

Draft Terms of Reference**Regional Acquired Brain Injury Implementation Group****AIM**

The aim of the multi-disciplinary, multi agency Regional Acquired Brain Injury Implementation Group is to improve on treatment, rehabilitation outcomes and support for children and adults with an Acquired Brain Injury. The Group will promote the independence of individuals with Acquired Brain Injury and the necessary support for parents, families and carers at all stages of the care pathway.

OBJECTIVES

The objectives for the Regional Acquired Brain Injury Implementation Group are:

- a) **Oversee implementation of the Acquired Brain Injury Action Plan, commencing in 2008/09. This action plan includes specific recommendations in relation to:**
 - Effective engagement and partnership working;
 - Service redesign (supporting people to achieve their full potential through enhanced service commissioning and provision);
 - Quality improvement and performance management;
 - Improved support for carers (including family support, information, advice and respite).

- b) **Ensure consistency in the development, quality and availability of services for people with Acquired Brain Injury across the region. This will include:**
 - More timely diagnosis and treatment;
 - Greater access to specialist expertise for patients, carers and staff;
 - Rehabilitation and social care support that enables people with Acquired Brain Injury to live as independently as possible;
 - Comprehensive and integrated care planning;
 - Easier access to services and useful information with clear points of contact;
 - Greater involvement of service users and carers in decisions that affect them and more opportunities to exercise choice; and
 - Improved support for carers/families.

- c) **Provide the DHSSPS and the Health and Social Care Board with advice on future development and costs of services for people with Acquired Brain Injury (adults and children) and their carers, taking account of recognised national and international standards and best practice.**

- d) **Provide advice to the DHSSPS, Health and Social Care Board, Public Health Agency and the Research & Development office of future research requirements in respect of Acquired Brain Injury.**

MEMBERSHIP

The Regional Acquired Brain Injury Implementation Group will adopt a core multi-disciplinary, multi-agency group approach which may change over time to address emerging needs. It is likely to require the formation of time-limited sub groups to consider particular issues, for example:

- Care pathways;
- Training and education;
- Creation of standards for the Acquired Brain Injury service;
- Development of family support, etc.

Membership of the sub-groups may extend beyond the core group.

Suggested membership:

- Chair
- HSC Board representation
- Local Commissioning representation
- HSC Trusts (at senior management level and senior clinical leaders)
- NITBIF/voluntary organisations
- Users x 2
- Carer x 2
- DHSSPS
- Nominees from other relevant Government Departments

It is recognised that membership of the group will need further discussion post 1 April 2009.

ACCOUNTABILITY

The Regional Acquired Brain Injury Implementation Group will be accountable to the Health and Social Care Board. It will produce an annual report on progress against the Acquired Brain Injury Action Plan, taking account of the terms of reference of the Group. On a quarterly basis, it will provide a summary of progress within each Trust area. These reports will be submitted to the Health and Social Care Board and copied to the Department.

Nominated HSC Trust Directors will provide a regular update on performance improvement within their respective areas.

TRANSITION ARRANGEMENTS

The Implementation Group should commence its work from April 2009. A brief progress report should be submitted to the Department by the end of July 2009.

DURATION OF GROUP AND REVIEW OF TERMS OF REFERENCE

The Group will co-ordinate implementation of the Acquired Brain Injury Action Plan 2008/09 – 2010/11. It will produce a final report on completion of that action plan. The terms of reference of the Group will be reviewed by the Health and Social Care Board in 2010/11 to determine the future needs of this Group and any changes to its terms of reference.