

# **REVIEW OF SERVICES FOR PEOPLE WITH ACQUIRED TRAUMATIC BRAIN INJURY IN NORTHERN IRELAND**

September 2008

This review was commissioned by the Minister for Health in March 2008 with a brief to examine the provision of services for people with acquired traumatic brain injury in Northern Ireland.

We have relied on the co-operation, openness and goodwill of clinicians, managers, service users and carers involved in, or affected by, traumatic brain injury throughout Northern Ireland and we wish to thank all those who contributed to our knowledge and awareness and made our work possible.

While our comments and recommendations arise from a comprehensive programme of engagement, they are the product of our collective reflection and not, in this sense, intended to be representative of the views of any other party.

Mr R Dixon (Chair)  
Professor D L McLellan  
Dr J Morgan

<b><u>CONTENTS</u></b>	<b><u>PAGE</u></b>
<b>1.0 Introduction</b>	<b>4</b>
<b>2.0 Executive Summary</b>	<b>5</b>
<b>3.0 Rehabilitation Medicine</b>	<b>9</b>
<b>4.0 Current service configuration</b>	<b>15</b>
<b>4.1 Commissioning of Traumatic Brain Injury Services</b>	<b>15</b>
<b>4.2 Inpatient and Outpatient</b>	<b>18</b>
<b>4.3 Community Based Rehabilitation</b>	<b>24</b>
<b>4.4 Voluntary sector Rehabilitation</b>	<b>28</b>
<b>4.5 Users, families and carers</b>	<b>32</b>
<b>5.0 Recommendations</b>	<b>34</b>
<b><u>APPENDICES</u></b>	
<b>A. Terms of Reference</b>	<b>38</b>
<b>B. Membership of Review Team</b>	<b>39</b>
<b>C. Questionnaire</b>	<b>40</b>
<b>D. Schedule of Visits</b>	<b>43</b>
<b>E. References</b>	<b>44</b>

## **1.0 INTRODUCTION**

### **1.1 General**

The review was commissioned by the Minister for Health, Social Services and Public Safety in response to concerns raised around the treatment and care of older people with traumatic brain injury. It was not the remit of the team to reinvestigate the care of any individual patient, but to consider overall the provision of services to people of all ages with this condition. The Terms of Reference are attached at **Appendix A**.

### **1.2 Terms of Reference**

Our remit was to map current service provision from the point at which medical stability was achieved and rehabilitation commenced; to highlight areas of good practice and significant gaps in provision, and to make recommendations. Throughout, we were to have regard for issues of equality.

### **1.3 Membership of the Review Team**

The review team comprised three individuals supported by a project manager. Short biographical sketches of the team members appear at **Appendix B**. Collectively, the team provided substantial and varied experience in rehabilitation generally and traumatic brain injury in particular.

### **1.4 Method of Working**

Through a comprehensive programme of meetings and site visits, the team engaged directly with a significant cross section of people and organisations active in traumatic brain injury across Northern Ireland. In addition to these meetings, the team issued a questionnaire and invited some written submissions. A copy of the questionnaire is attached at **Appendix C** and a full schedule of the meetings is attached at **Appendix D**.

### **1.5 Constraints**

Six months on a part time basis is a short time to map and report on services of this complexity. We have made specific recommendations where possible but we have also indicated certain areas in which further fact finding and analysis needs to be done by the Department of Health, Social Services and Public Safety or by Commissioners in order to address what appear to be shortfalls in current services.

### **1.6 Production of Report**

Throughout the process, the team conferred regularly, and agreed its conclusions and recommendations once the programme of meetings was complete.

## **2.0 EXECUTIVE SUMMARY**

The report, having stated the function and parameters of the review, deals in turn with the planning and commissioning of services and their provision by Trusts through inpatient and outpatient services, through community based services and through the independent sector. A general overview of the findings of the engagement is then presented, followed by conclusions and recommendations for action.

The whole is prefaced by a discussion of rehabilitation medicine, particularly its development, functions and purposes. It is important to be clear about the nature of this clinical speciality, and specifically to understand how rehabilitation of the brain injured person differs from that provided for people recovering from stroke and for those suffering ill health in old age.

The following paragraphs summarise in a few sentences, the more detailed commentaries to be found under each subject heading.

### **2.1 Current service configuration**

#### **2.1.1 *Commissioning***

A priority given to brain injury in the past 10-15 years is apparent through the existence of the Regional Acquired Brain Injury Unit (RABIU) and the establishment within each Trust area of a Community Brain Injury Team (CBIT), led by a Consultant Neuropsychologist. In addition, there is a diverse independent sector active in brain injury supported – at least in part – by commissioners. The team acknowledge and commend these initiatives.

There is no overall plan, however, for the provision and development of services and performance management of them at the level of commissioning or strategic planning. This needs to be introduced.

#### **2.1.2 *Specialist Inpatient and Outpatient***

A range of inpatient and outpatient services is available, appropriate in their function to the complex needs of people with traumatic brain injury. However, there tends to be a lack of options for onward referral within inpatient units. This leads to delayed discharge across the system which hinders the capacity of each of these services to respond adequately to new referrals and to develop in response to need. There are few examples of case management or formal co-ordination of the rehabilitation pathway in hospitals but the Community Brain Injury teams appear to perform this essential task effectively in the community, once patients have been referred to them.

The RABIU is appropriately resourced and equipped for its purpose. It is to a degree hindered by the inability to refer on, in a timely manner, those patients who have completed their programme and who require specialist and complex ongoing support in other services. This is particularly the case for people in minimally responsive states and those who exhibit challenging behaviour.

RABIU is publicly perceived by families/carers as the source of the best treatment and care in brain injury. This may be partly the result of its visibility, a lack of service co-ordination and the need for effective dedicated family support at a traumatic time. It may also arise from the need to communicate more clearly to families that RABIU is only one element in a continuum of rehabilitation. The effect is that families may be reluctant to see their family member referred on to other services of which they have less knowledge and in which, therefore, they have less confidence.

Thompson House is a high quality environment with current capacity for further development that would ensure onward referral of patients in minimally responsive states to reduce pressures on RABIU.

Maine Villa requires infrastructure investment to enable it to provide a higher quality of care and to admit women.

Both Thompson House and Maine Villa suffer from the lack of options for onward referral of patients. In the case of Thompson House, this would be for the care of patients with tracheostomies in particular and in the case of Maine Villa this would be for the provision of independent and supported living options.

Spruce House has the potential to offer additional service to a wider brain injured population. It is an underused resource at present.

### **2.1.3. Community**

There is a Community Brain Injury Team in each Trust area and so a degree of equity of access for patients across Northern Ireland. However, the type and level of service offered does vary. In some areas, a comprehensive range of stand alone services are offered, in others, the Community Brain Injury Team is able only to assess patients and seek their referral into generic services – for example, within physical and learning disability programmes of care.

### **2.1.4 Voluntary Sector**

The independent sector, inside and outside Northern Ireland, deliver a variety of services on which the statutory sector is dependent. In the main, the key link between the statutory and independent sectors is provided through the Community Brain Injury Teams.

Services are not equally distributed geographically, with the bulk of such services available in the more heavily populated Eastern part of Northern Ireland. In addition, the range of services offered varies across the spectrum of severity with a preponderance of services provided for those capable of reasonable independence.

That these services are essential – not optional – is of particular importance. Without independent sector activity there would be few, if any options for supported living, residential care, pre-vocational and vocational training or social reintegration of people with brain injury in Northern Ireland.

### **2.1.5 Services for Older People**

Given the expected incidence of TBI in older people, we were surprised by the lack of data relating to this group of patients, either in relation to dedicated services or a clinical profile. The clinicians we spoke to had not identified this group as presenting a particular pressure within the service, the presence of concurrent illness, particularly dementia, giving rise to a low expectation of what rehabilitation was likely to achieve.

Where there are services for such people provided in the context of stroke or general rehabilitation, it does not appear that these are services ideally suited in all cases to the particular needs likely to arise after acquired traumatic brain injury, and which would require specialist rehabilitation input.

### **2.1.6 Stroke Services**

Many of the key brain injury services accept referrals of young and complex strokes – those where particular behavioural and cognitive challenges arise. This is not universally the case, however. We note that the recently published Stroke Strategy acknowledges the need for psychological input to community stroke services since a lack of such expertise impedes the ability of services to respond appropriately, either to people with a traumatic brain injury or complex stroke (who are accepted by community brain injury teams in some areas).

### **2.1.7 Services for children and adolescents**

There is no dedicated clinical rehabilitation specialist working with children at present. Inpatients are managed by paediatric neurology in an unsuitable environment, and there is no systematic follow-up, except through generic community children's services.

### **2.1.8 Services for families and carers**

Brain injuries often affect family life, and may impose significant demands upon all those close to the injured person. There is a need to recognise and develop further the provision of accurate information and the specialised support required, from the immediate aftermath of the initial trauma to the long-term difficulties that may be experienced.

## **2.2 Equality**

There are excellent services and significant additional potential. However, because of the piecemeal nature of the development of these services to date there are variations across the system in the range of services available in different areas and for different groups of people. Attention should be focussed on the following matters to ensure equitable access to specialist services:

- Services for older people and for children;
- Common referral protocols;
- Locations where fewer service options exist;
- Blocks to onward referral;
- Options for the long term care of people with higher levels of need; and
- Services for women with challenging behaviour.

## **2.3 Conclusions**

There is a substantial range of services available to people with traumatic brain injury in Northern Ireland addressing need at all stages of the rehabilitation continuum.

The majority of these services have arisen through local or service specific initiatives – rather than within a co-ordinated strategic approach to care for this patient group in Northern Ireland.

As a result, while there are excellent facilities and much to commend in the individual services themselves, there is also some unevenness in terms of availability of and access to services, suboptimal use of some resources and some specific gaps in service – particularly in the provision of children’s rehabilitation and long term community based options for patients.

There appears to be confusion among commissioners as to the extent to which patients with stroke and acquired brain injury have different needs. The service provided to elderly people after an acquired traumatic brain injury requires formal evaluation.

The management of transitions in service provision between children’s and adult services and adult and elderly people’s services is haphazard and probably leads to different approaches in the rehabilitation received by different individuals on the basis of age despite recent attempts to prevent this.

The lack of options for onward referral can create problems for inpatient services. This makes it likely that the best potential of these resources is not being fulfilled.

Certain elements of the service could be more effectively linked and a co-ordinated programme of care commissioned for a brain injured person from the actual incident through to long term support and care would improve service provision.

## **2.4 Recommendations**

The key recommendation is for regional management of brain injury services under a Managed Clinical Network. This immediately necessary work should ensure the following:

- Agreed protocols for referral across the services
- A comprehensive care pathway for all patients supported by a case management system of coordination
- A regional strategy for priorities for investment and further development

Further and more detailed recommendations appear in the body of and at the end of the report.

### **3.0 REHABILITATION IN THE NHS**

The Health Service provides medical and surgical assessment and treatment in the course of which specific disease processes are identified and treated, with the aim of eradicating the disease if possible or at least containing the disease process. At the same time, all necessary measures are taken to relieve any suffering associated with the disease.

When impairment of function cannot be repaired by natural recovery or by medical treatment, rehabilitation then helps patients to optimise their level of function, autonomy and participation in society.

Medical treatments are generally specific to the disease concerned, and it may therefore be appropriate for medical services to be developed and implemented for specific conditions such as cancer or stroke.

Rehabilitation by contrast uses techniques that are specific to functional impairments irrespective of the disease that has caused them. The application of these techniques will then be tailored to the patients' particular attributes, needs and social circumstances.

#### **3.1 Commissioning for Rehabilitation**

Commissioning rehabilitation services according to traditional medical disease categories thus risks excluding from some rehabilitation services some individuals whose rehabilitation needs are similar, purely on the grounds that their medical needs have been different. This inevitably leads to inequities in the way that different individuals' rehabilitation needs are met.

The skills and resources of social services as well as health related therapies and Rehabilitation Medicine are needed for most rehabilitation programmes. For the reasons outlined above, needs categories tend to be adopted in community rehabilitation and social services. Community physical disability teams thus provide a generic service appropriate to many disabled people with a range of different medical conditions.

That there are unitary Health and Social Services in Northern Ireland should ensure the efficiency and effectiveness of community rehabilitation services to the population of Northern Ireland by enhancing practical collaboration and the sharing of expertise between the Health and Social Services.

#### **3.2 Equity Issues in Rehabilitation**

Equity of effective provision is a challenge to all rehabilitation services and may be compromised by the following factors:

##### **3.2.1 *The nature and complexity of the impairments giving rise to the need for rehabilitation.***

Current rehabilitation services tend to be configured to meet the commonest patterns of impairments, such as physical disability or mental health problems (including addiction to drugs and alcohol) or cognitive problems such as dementia.

- a. These services are likely to have been developed and resourced at Trust level rather than strategically, and in any one geographical area may differ in their effectiveness.

- b. Patients with complex impairments such as a combination of physical and cognitive problems may be referred to a service (e.g. a physical disability service) that can fully address only part of their problem, the other part, or parts, being inadequately addressed. Particular difficulties tend to be experienced by patients with severe sensory impairments- such as blindness- together with physical and cognitive impairments, or those who need help with a combination of physical, cognitive and mental health problems.
- c. Some elements of resource are in particularly short supply (for example, clinical psychologists, the provision and monitoring of complex communication aids, specialists trained in rehabilitation medicine, services for those with very severe behavioural disorders, services for adolescents with cognitive problems).

### 3.2.2. *The age of the disabled person*

Children, younger adults, older adults and elderly people tend to differ in terms of:

- a. **their objectives in rehabilitation.** For example, children need to acquire basic skills and education; younger adults need more help in understanding the implications of their condition and in establishing themselves in employment and in starting a family, older adults may have more experience of life and of problem solving but less ability to recover function spontaneously after an injury. Elderly peoples' objectives are necessarily constrained by their age and the presence of other diseases common in old age, but their past experience of problem-solving may boost their response to rehabilitation when appropriate help is offered to them.
- b. **the methods and techniques that services have to employ in order to achieve rehabilitation most effectively.** For example, family members are crucial influences and have to be supported in all children's rehabilitation. Learning skills and personal and social independence have to be acquired in young people who have not already developed them. Young adults need much more intensive and demanding programmes of rehabilitation than most elderly adults.
- c. **the environments in which services have to be delivered.** For example, in schools (children), college (teenagers and young adults), places of work (younger and some older adults) and a variety of home and community settings (all ages)
- d. **the concurrent presence of a number of different disabling diseases** (especially in elderly people) that may restrict the ability to exercise or to perform tasks that a younger person could still expect to achieve.

### 3.2.3 *The particular circumstances and attributes of the disabled person*

Unlike the treatment of illnesses with drugs, rehabilitation services have to be flexible enough to address the differing needs of individuals resulting from a very wide range of personal attributes, environments and objectives. This requires a wide range of skills and inventiveness from rehabilitation staff. They need to be able to understand and work with all comers, taking due account of a wide range of personal and cultural matters that have a huge impact on the rehabilitation that has to be given (but by contrast are largely irrelevant in determining the prescription of medical and surgical treatment).

### 3.3 Acquired Traumatic Brain Injury

Acquired Traumatic Brain Injury has been particularly highlighted by difficulties that have arisen in the United Kingdom and elsewhere in providing effective rehabilitation for people recovering from acquired traumatic brain injuries and support for their families (ref: Welsh Affairs Committee 1999 and Health Select Committee 2002 Reports, HMSO), difficulties that have surfaced again in Northern Ireland and led to the current review.

### 3.4 Why does Acquired Traumatic Brain Injury pose such a challenge to Health Services?

The three major reasons are:

- a. The complex physical, cognitive consequences of such injuries (reflecting a combination of widely diffuse axonal injury together with focal areas of brain damage)
- b. The complexity and sophistication of the rehabilitation techniques needed to achieve rehabilitation after such a pattern of injury and the range of experienced professional input that is necessary
- c. The wide range of social situations (and hence specific aims of rehabilitation) which differ greatly between children, adults and elderly people.

It is evident from the discussion above that delivering equitable services to people with ABI of all ages in all parts of Northern Ireland requires strategic planning and service implementation.

### 3.5 Rehabilitation after Acquired Brain Injury (ABI) and Acquired Traumatic Brain Injury (ATBI): the relationship between stroke, trauma and other causes of ABI.

ABI is, in essence, any damage to the brain caused after birth, either by illness or trauma. Traumatic injury to the brain (ATBI) tends to cause a combination of both **diffuse** and **focal** brain damage:

**Diffuse** damage breaks connections between nerve cells and tends to cause complex disturbances of cognition and behaviour. The time course of recovery of abilities is relatively prolonged (at least 2 to 3 years in more severe cases) and depends upon sustained and repeated practice for its completion.

By contrast, **focal** damage (for example, stroke caused by haemorrhage into the brain substance or by blockage of a major artery in the brain) causes death of all neurones in the centre of the damaged area; only those around the margin of the lesion are potentially recoverable while the rest of the brain is normal. Recovery after a focal lesion alone (as in most cases of stroke) occurs over a significantly shorter timescale (6 to 12 months) and is much less likely to cause disturbed behaviour, impaired cognition usually being milder and less overt than after diffuse injuries.

Diffuse damage with its characteristic consequences is also common after subarachnoid haemorrhage, viral encephalitis and hypoxic brain damage (caused for example by near drowning, prolonged cardiac arrest or serious drug overdose). Thus patients recovering from these conditions will need the same kind of rehabilitation as those with acquired traumatic brain injury (ATBI).

Stroke is far more common than any of these causes of diffuse brain damage but there will also be a small percentage (perhaps 5%) of strokes who therefore need a similar pattern of rehabilitation input to those with traumatic brain injury.

### **3.6 Age and Rehabilitation Need after ATBI**

There are peaks in incidence of traumatic brain injury in early childhood, and at ages 16-24 and 65-75.

Although biological survival and recovery is generally better in younger people, injury in infants and young children disrupts the brain's basic processes of development and those younger than about 8 or 9 years of age are particularly vulnerable and likely to experience long term consequences after severe injury.

Children initially start to recover from traumatic brain injury faster than adults, encouraging optimistic forecasts of recovery. However, because the brain's development is impeded after significant injury, they may then gradually diverge progressively from their peers at school and increasingly fall behind them in social and academic development. The challenge here is to pick up this pattern of events as early as possible so that special attention can be given to the child's social development and school performance before the child becomes demoralised by failure and falls too far behind. For this reason, follow up of head-injured children is particularly important. Medical and therapy input is from children's health services (paediatric neurology, otherwise developmental paediatrics or general paediatrics)

Teenagers and younger adults are still completing their education or establishing themselves in careers and family relationships. They have more physical resilience than older adults but relatively little experience of adult life and of coping with illness (especially an illness with such complex consequences of a significant ATBI) and thus need an expert and intensive rehabilitation input to overcome the effects of their injury.

Older adults, by contrast, may recover more slowly and less completely from the initial impact but their rehabilitation potential may be enhanced by their pre-injury experience of problem-solving and of overcoming adverse life events.

In old age, other common medical conditions such as heart, musculo-skeletal or pulmonary disease are often present and may restrict the capacity to respond to rehabilitation. In some, a head injury may reveal that a latent dementia was already present. At this stage of life, people tend to have fewer life goals still to achieve and so the aims of rehabilitation are more circumscribed. Geriatric medical services have therefore tended to take responsibility for the rehabilitation not only of older stroke patients (70% of strokes occurring in people over the age of 65) but also elderly head injured and other elderly ABI patients.

### **3.7 Involvement of medical specialties and other rehabilitation professions in rehabilitation after ATBI**

These relationships are spelled out in the Report of the Royal College of Physicians (*Medical Rehabilitation for People with Physical and Complex Disabilities*, 2000) and are replicated throughout Europe, America and Australasia (*The Rehabilitation "White Book"*, European Board of Physical and Rehabilitation Medicine, 2007).

#### **3.7.1 Age Considerations**

Paediatric medical services have traditionally taken the lead in providing medical and rehabilitation input to children, in collaboration with education and social services. All severe injuries should be managed by a neuropaediatrician. Rehabilitation Medicine is relatively young as an independent medical specialty (established in Scotland in 1975 but in the rest of the UK only since 1998) but is the only medical specialty whose training specifically includes a major component of brain injury rehabilitation.

This is essential in providing specialist medical services for children and elderly people to ensure that patients in the transitional stages from childhood to adulthood and from adult to elderly care receive an appropriate level and standard of rehabilitation. There are currently about 150 consultants in rehabilitation medicine in the UK, although the recommended allocation is one consultant for every 200,000 of the population. This by European standards would still be a very modest level of provision, (Ref *The White Book of Rehabilitation Medicine in Europe (2007)*; *Rehabilitation Medicine: The National Position in 2007*).

In addition, neuropsychiatric expertise may be essential for certain individuals whose behaviour is aggravated by a psychiatric disorder either predating the brain injury or newly developed as a consequence of it. Residential rehabilitation units for patients with particularly disturbed and aggressive behaviour are generally headed by a specialist in adult neuropsychiatry.

Geriatric medicine has traditionally taken the lead in relation to older people over 65 who do not as a rule require vocational rehabilitation as part of their package but who are likely to have complex and interacting medical needs due to other concurrent disabling conditions that are commonly present at this stage of life.

### **3.7.2 Transitions**

While there is thus good reason for these age-related divisions of service, it is essential that proactive liaison takes place across the ages of transition from childrens' to adults' services to services for elderly people. Rehabilitation need rather than precise biological age should determine the service to which individual patients are admitted, and the time at which they transfer from one service to another.

## **3.8 Role of Professional input to Rehabilitation**

### **3.8.1 Hospital stage**

While such medical input is particularly important in the acute and early stages after injury, the principal thrust of rehabilitation in most cases is provided by the health related rehabilitation therapies, principally physiotherapy, occupational therapy, speech and language therapy and clinical psychology. Rehabilitation nursing is a crucial component of inpatient rehabilitation and in other regions of the UK, the appointment of nurse brain injury co-ordinators has proved very effective in liaising and facilitating patients' passage along the rehabilitation pathway through the hospital and into the community.

### **3.8.2 Community stage**

Health and social services have to work closely together in all community rehabilitation and the fact that there are unitary authorities in Northern Ireland should greatly help in this. Community disability teams are generally led by therapists across the UK but clinical psychologists are increasingly taking the lead both in specialist community brain injury rehabilitation teams and in community based brain injury rehabilitation units. It is important that the relevant medical specialists (as above) are readily available to such teams for those patients whose medical needs impact upon their rehabilitation.

The rehabilitation of people recovering from ATBI is thus far more than a process of discharging people from hospital – in most cases this is simply the start of a much longer but equally challenging process of personal development and social reintegration, including return to employment.

### 3.9 The Rehabilitation Pathway for ATBI

The recommended clinical pathway for moderate and severe cases of ATBI is complex and may be summarised as follows:

1. **Admission to A and E: Initial Triage and Screening**
2. **Transfer to Neurosurgery/Intensive Care** – otherwise, directly to Children's Ward (children) or Adult Ward either
  - a. Surgical Ward relevant to any surgical investigation and treatment required
  - b. Medical ward until medically stable

They should be picked up here by a rehabilitation co-ordinator responsible for facilitating their passage along the pathway until picked up by a community services at **Stage 5** below.

3. **Transfer to Rehabilitation Ward or, if necessary, directly to RABIU** (some patients may move directly to **Stage 4** at this point)
4. **Planned discharge either to home with follow-up and support, if necessary, or to a slow stream rehabilitation unit, or unit for profound impairment (such as an established minimally conscious state or unit for rehabilitation of severe and refractory behavioural disturbance.**
5. **Community rehabilitation at home or in a residential unit supported as necessary by outpatient reviews from RABIU or relevant medical and surgical specialities Co-ordinated by a case management system** that has taken over from the hospital rehabilitation co-ordinator. Specialist vocational rehabilitation and respite care provision may be relevant at this stage.

**4.0 CURRENT SERVICE CONFIGURATION**

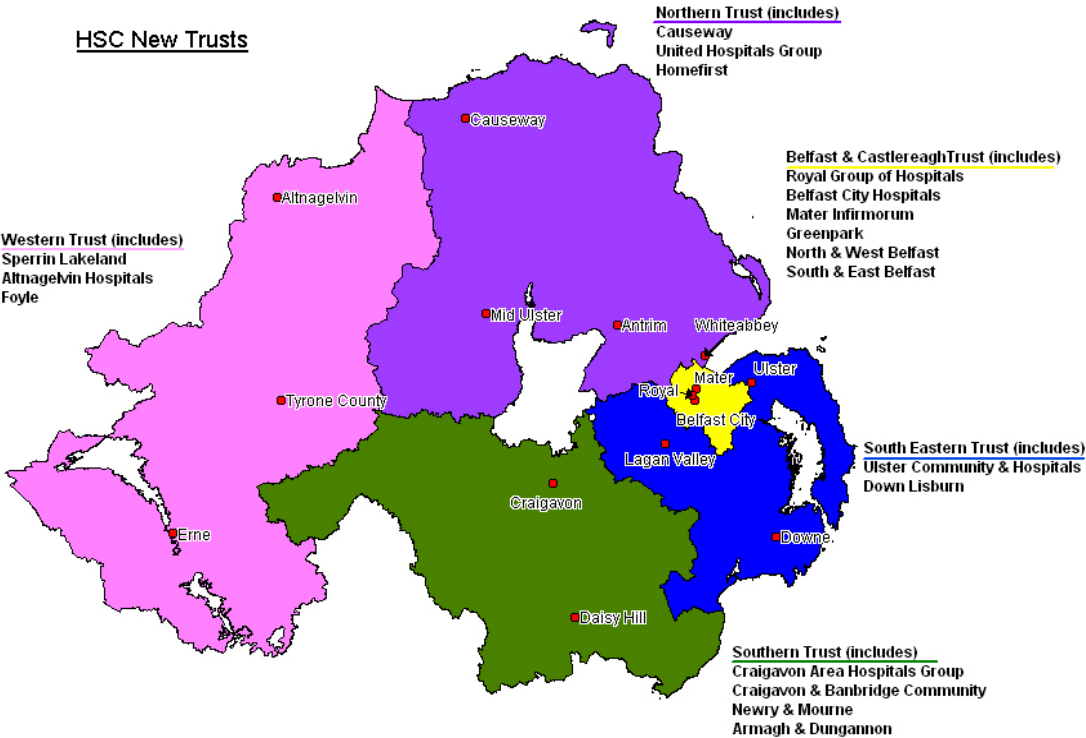
**4.1 Commissioning of Traumatic Brain Injury Services**

**4.1.1 Board and trust configurations**

Currently in Northern Ireland services for people with acquired traumatic brain injury (ATBI) are commissioned by four Health and Social Services Boards (HSSBs), from five recently consolidated Health and Social Care Trusts (table 4.1). However, this commissioning picture will change next year with the ongoing Review of Public Administration (RPA), when commissioning will move to one centralised regional authority.

Table 4.1 Financial allocation for ATBI services

Service Commissioner	Health and Social Care Trusts	IP/OP services	Community services	Voluntary services
Eastern HSSB Pop: 670,000	Belfast Trust South Eastern Trust	£2.51m £850,000	£ 385,000 £ 348,000	£ 523,000
Northern HSSB Pop: 444,000	Northern Trust	£524,000	£ 575,000	£ 208,000
Southern HSSB Pop: 321,000	Southern Trust	£ 392,000	£ 320,000	£ 77,000
Western HSSB Pop: 290,000	Western Trust	£ 464,000	£ 545,000	£ 230,000



Certain specialist services and facilities, although located in specific Trusts, provide regional services. The Regional Acquired Brain Injury Unit in Belfast, Thompson House Hospital in Lisburn and Maine Villa in Belfast all provide specialist inpatient rehabilitation and have contractual performance relationships with four Boards while being located within the Eastern Board.

Some boards also commission and fund specialist services in England and Scotland, only after extensive patient assessment and consideration of local alternatives. For example severely challenging behaviour in female patients almost always entails out of area placement. Currently nine adults are in receipt of services in facilities such as the Transitional Rehabilitation Unit, Liverpool, St Andrew's Hospital, Northampton, and Brain Injury Rehabilitation Trust (BIRT) facilities. Each Board funds these placements with non-recurrent monies as an extraordinary pressure; their current cost is shown in Table 4.2.

Table 4.2 Cost and geographical breakdown of out-of-area placements

Service Commissioner	Number of Out of Area Specialist Placements	Total Cost of Out of Area Placements
Eastern HSS Board	3 Male 2 Female	£750,000
Northern HSS Board	2M 1 F	£441,000
Southern HSS Board	- -	- - -
Western HSS Board	- 1 F	£200,000
<b>Total</b>	<b>5 M 4F</b>	<b>£1.39 million</b>

One commissioner did suggest that if some form of bridging or development finance were made available for a parallel period, many of these patients could be repatriated and managed appropriately closer to their families, with a view to sustaining the newly-developed services for future patients.

In addition, a number of Trusts consulted are also providing very intensive 24 hour domiciliary support packages, costing up to £150,000 per annum for patients in the absence of any viable residential or supported living options.

#### 4.1.2 Epidemiology of head injury in Northern Ireland

Incidence and prevalence of a condition as heterogeneous as traumatic brain injury are notoriously difficult to estimate by using ICD (international classification of disease) coding data collected routinely on A&E and hospital admission. There are many reasons for this, not least because brain injury may go unrecognised in many trauma patients, who require acute medical interventions for their other injuries.

Table 4.3 Routinely collected data on head injury – Northern Ireland 05/06 and 06/07

Service Provider Area	Incidence of SO6 and SO9 Admissions 06/07	Incidence of SO6 and SO9 Admissions 05/06.
Belfast HSC Trust Pop: 334,000	250 SO6 536 SO9	236 SO6 496 SO9
South Eastern HSC Trust Pop: 336,000	59 SO6 215 SO9	67 SO6 261 SO9
Northern HSC Trust Pop: 440,000	98 SO6 475 SO9	57 SO6 414 SO9
Southern HSC Trust Pop: 321,000	63 SO6 731 SO9	55 SO6 472 SO9
Western HSC Trust Pop: 290,000	66 SO6 324 SO9	76 SO6 304 SO9
<b>Total pop 1.73million</b>	<b>536 SO6 2281 SO9 (2817)</b>	<b>491 SO6 1947 SO9 (2438)</b>

Extrapolation from aggregated coding data for other parts of the UK (again imperfect) would suggest an incidence of approximately 22,800 for Northern Ireland's population of 1.73m, of whom 10% or 2,300 should require hospital

admission. This extrapolation is broadly in line with the figures supplied to us by the Department

ICD codes:

- SO6 – Intracranial injury
- SO9 – other and unspecified injuries of the head not classified elsewhere

Extrapolation from aggregated UK coding data (again imperfect) would suggest an incidence of approximately 22,800 for Northern Ireland's population of 1.73m, of whom 10% or 2,300 should require hospital admission. Although coding data for 06/07 indicate a higher number than expected, this cannot be interpreted meaningfully for reasons alluded to above.

#### **4.1.3 Strategic and policy context**

The senior commissioners, although indicating that they had established a four board planning group to look jointly at issues concerning ATBI, agreed that the absence of a specific, over-arching Departmental strategic vision or action plan had affected the operation of any joint activity planning, and the development of any specific performance framework in this service area. Likewise the Department of Health, Social Services and Public Safety (DHSSPS) had not identified brain injury in their strategic Priorities for Action. However brain injury is specifically referenced in "A Healthier Future – a 20 Year Vision for Health and Well Being in Northern Ireland" in 2005. In that document, co-ordination of the many brain injury services was commended, as was the development of a fresh strategic direction for physical, sensory and brain injury services.

Commissioners consulted were in favour of a regional network or framework to plan and manage the care pathway and delivery of services to any agreed strategy. They confirmed that services currently delivered - particularly in a community context - were commissioned and funded according to programmes of care, and acknowledged that a significant current gap was the provision of specialist care and support to children with a head injury (specifically up to 16 years). With respect to provision of services to people over 65, whilst this had been identified as an emerging need, it had not been prioritised by programmes of care at the commissioner level to the same degree as in adult services.

Commissioners acknowledged differences in both real and pragmatic terms that had resulted in differences between the teams providing community services. Both Southern and Northern Health Boards reported some rehabilitation medicine outreach support to community brain injury services from the Belfast base for rehabilitation medicine. This is not yet available to the Western Board.

Commissioners also indicated that the Regional Brain Injury Unit opened in 2006. Since then, the development of performance monitoring and management information between the Trust and the Commissioning Boards has not progressed as they would have wished.

These issues need to be addressed at a strategic level. However commissioners also reflected that the increasing insistence on ring-fencing of funding through the comprehensive spending review, leaves very little scope for any flexibility in redirection of resources. Likewise, the departmental streaming of programmes in separate silos means that pooling of resources is very difficult in reality. All commissioners confirmed their reliance on a mixed economy of key service provision from the independent sector. Some key pressures reflected and expressed by commissioners included the need for enhanced services for children, those in

minimally responsive state, including those with tracheostomies located in hospital settings, and those with enduring severe behavioural problems, including women now in receipt of care/support out of area.

Commissioners suggested that partnership with local specialised providers or redesign of current provision ensuring service flow might address this. Commissioners also indicated that sound informational data on need was an essential basis to any forward service planning. The use of already published information such as National Service Framework on Long term Conditions 2005, also identified clear quality requirements applicable to the design and delivery of service to people with brain injuries, for life.

#### **4.2 Inpatient and Outpatient**

Inpatient rehabilitation for adults (defined as age range 16 – 64 years) with acquired brain injury (ABI) in Northern Ireland is delivered within four units, located almost exclusively within the Eastern part of the province. The Belfast Health Care and Social Trust (BHCST) hosts two of the units (Regional Acquired Brain Injury Unit and Maine Villa); the South Eastern Trust a third (Thompson House Hospital) and the fourth is accommodated in the grounds of Altnagelvin Hospital, Derry within the Western Health Care and Social Trust (Spruce House).

Table 4.4 Staffing profile - adult inpatient brain injury services – by Trust  
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			
<b>Total Staff</b>	<b>95.20 w.t.e.</b>	<b>29.97 w.t.e.</b>	<b>49.77 w.t.e.</b>	<b>26.41w.t.e</b>

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

**4.2.1 The Regional Acquired Brain Injury Unit (RABIU)** comprises 25 beds and is a purpose-built structure opened in 2006, within the grounds of Musgrave Park Hospital in Belfast.

Two consultants in Rehabilitation Medicine provide clinical leadership. The team admits patients from all areas of Northern Ireland with a range of presentations after ABI including challenging behaviour, vegetative states (VS) and severe physical disability. Its inpatient treatment is complemented by an active and well-staffed multidisciplinary outpatient service (306 patients treated in 2007), which is currently offered only to those living within commutable distance of the unit.

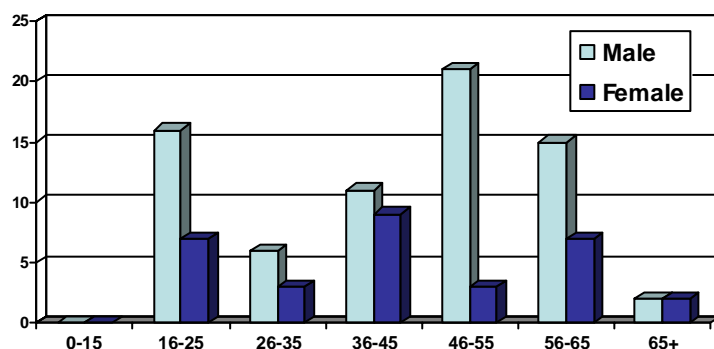
The initial business case for the unit suggested a treatment brief limited to those with traumatic brain injury, but this was expanded to include patients with complex disability after all forms of acquired brain injury, predominantly in the adult population (16 – 64 years). Individuals outside that age range are not excluded from the unit, but must demonstrate at assessment a potential to benefit from the intensive rehabilitation process offered, and be relatively free of significant co-morbidities.

240 referrals were received by the unit in 2007, 209 of them from acute hospitals, particularly the neurosurgical wards in the Royal Hospital. Of those referrals, 152 were admitted (6 >65 years), one third of whom had sustained a stroke. The average length of stay was 52 days, and the time from placement on the waiting list to admission was reported as being 24 days. Of note is an anecdotal absence of agreed criteria between RABIU and region-wide stroke units to determine which selected patients might derive the greatest benefit from the intensive approach offered on the RABIU.

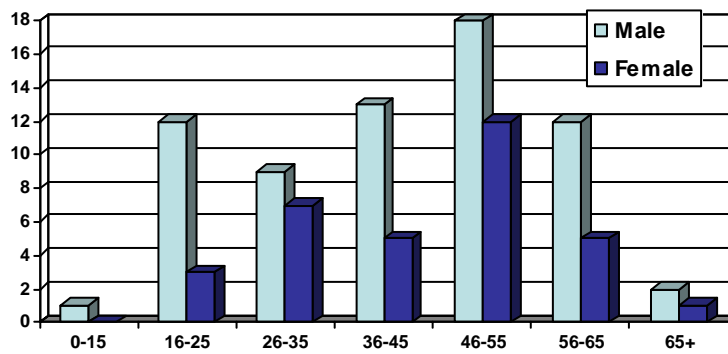
As would be expected from such a comprehensive and highly skilled team, the rehabilitation process is rigorous and systematic, with evidence of weekly interdisciplinary goal-setting; use of a key worker system and collaborative documentation; collection of multi-faceted outcome measures, and regular and extensive consultation with family members.

The patient flow through the unit has slowed in recent months, as the accumulated effect of delayed discharges (to other acute and community facilities) has become apparent. The average length of stay is affected by the time taken to discharge VS patients to alternative facilities such as Thompson House Hospital. The challenging behaviour unit is unable to admit female patients, hence compounding the issue of inequity of access for behaviourally disturbed females (see Maine Villa) to appropriate and timely management.

Percentage of RABIU Inpatient Attendances by Age and Gender 2007/08



Percentage of RABIU Outpatient Attendances by Age and Gender 2007/08



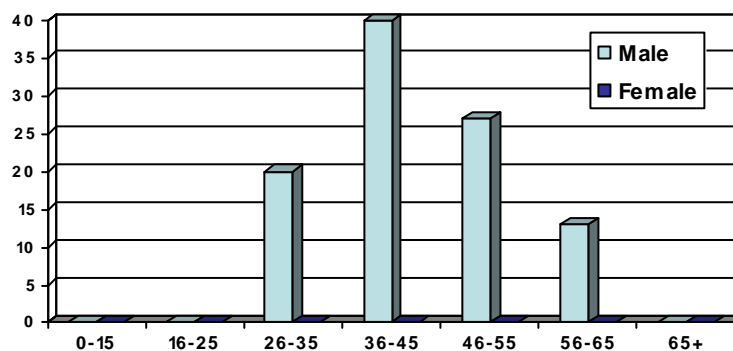
**4.2.2 *Maine Villa*** is a 15-bedded facility located on the grounds of Purdeysburn Hospital (mental health services) in Knockbracken, Belfast, and is concerned exclusively with the management of adult males presenting with significant behavioural difficulties after ABI, who cannot be accommodated in any other setting.

A Consultant Neuropsychologist provides clinical leadership, with sessional input from Northern Ireland's only Consultant Neuropsychiatrist. Additional staffing is provided by mental health nurses and a part-time occupational therapist, but no physiotherapist or speech and language therapist input.

Owing to the dormitory style accommodation, females cannot be admitted to this unit. This feature of the unit also mitigates against optimum management of behaviourally disturbed individuals, particularly those who have been resident in the unit for many years. Given the limitations imposed by the unsuitable environment, the rehabilitation process appears to be rigorous, highly organised and well monitored.

Only 2 of the 15 beds are available for early admission of behaviourally disturbed males: the remainder are occupied by those awaiting (i) more suitable (but currently non-existent) supported community placement, and (ii) out-of-area residential treatment in England (Transitional Rehabilitation Unit in Liverpool and the Kemsley Unit in Northampton).

Percentage of MAINE Inpatient Attendances by Age and Gender 2007/08



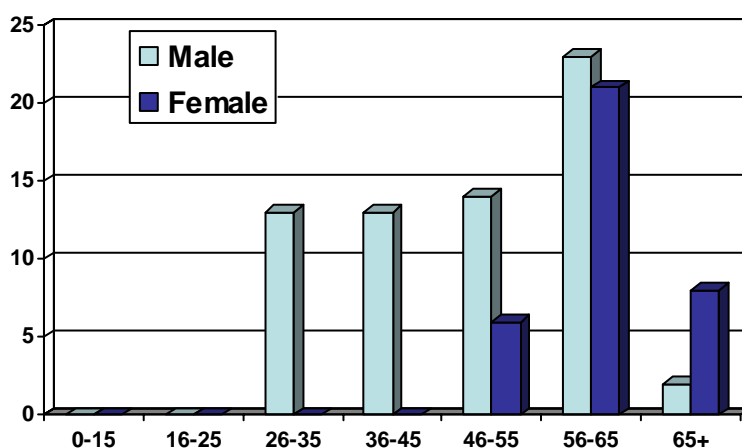
**4.2.3 Thompson House Hospital (THH)** is a 40-bedded unit of which 35 beds are currently commissioned. It offers long-term residential care and some rehabilitation / respite to adults (16 – 64 years) with neurological disability. THH gained CARF (Commission of Accreditation of Rehabilitation Facilities) accreditation in 2003, the only organisation in Northern Ireland to have achieved this milestone. The environment is very attractive following a recent £3.6 million pound refurbishment.

Referral sources include the Neurology service within the Royal Hospital; the Community Brain Injury Team; the local physical disability team; and the RABIU. Approximately 7 beds are allocated for slow stream rehabilitation of patients with significant disability after acquired brain injury. Currently only 4 of those beds are accessible by appropriate ABI patients, as 3 of the beds are occupied by patients with tracheostomies who cannot be discharged to alternative facilities. The average length of stay in the 4 slow-stream ABI beds is 2 years.

22 of the remaining beds are allocated for continuing care – ie long-term residential care of patients whose needs cannot be met in independent residential facilities. Of those 22 beds, patients who are in a low awareness state after an ABI currently occupy 11. Respite care and maintenance rehabilitation is offered to a small group of selected patients, within 4 allocated beds. The issue of clinical leadership is somewhat ambivalent however, with no defined forum for formal goal setting; a Consultant Neurologist provides medical input once a week. The therapy and nursing teams meet once a week, and the neurologist meets with family members and other clinicians on a different day.

One particular issue of note is a group of patients in the unit with tracheostomies (4). The unit avails of willing but ad-hoc support from the Anaesthetic and Neurology departments in the Royal Hospitals with regard to tracheostomy management. There appears to be no formal programme in place to encourage late decannulation, scheduled tube changes, or emergency transfer in the event of acute respiratory compromise.

Percentage of Thompson House Hospital Inpatient Attendances by Age and Gender 2007/08



**4.2.4 Spruce House** is a 24-bedded purpose-built neurodisability unit on the grounds of Altnagelvin Hospital in Derry. It opened in 2004, but only 18 of its beds are commissioned at this point in time. Referrals are derived from many sources, almost half coming from the adjacent acute hospital. Clinical leadership is provided by an acting senior nursing manager, with one session of medical input from a Consultant Rheumatologist, and three sessions from local GPs.

Beds are allocated equally among long-stay (6), respite (6) and slow-stream rehabilitation (6) patients. Some of the slow stream patients are repatriated from RABIU, and average length of stay in these beds is about 5 months.

Despite a recent increase in therapy treatment time, more is needed (10 hours physiotherapy per week). The nursing team and Trust senior management are enthusiastic and keen to increase their ability to offer a more responsive and intensive service, as soon as funding for a Consultant in Rehabilitation Medicine and supporting therapy team can be approved.

**4.2.5 Children's services.** The review team visited only one paediatric ward – at the Royal Children's Hospital in Belfast where all children with severe injuries requiring neurosurgical evaluation and treatment are cared for when they leave the neurosurgical department. The inpatient environment here is not suitable for brain injury rehabilitation and the rehabilitation facilities are inadequate in scale and resource. The paediatric neurology service is very short of consultant input and for this reason very few children receive specialist follow-up after being discharged from hospital. This is likely to have adverse consequences for a significant proportion of children with moderate and severe brain injuries. We are unable to comment upon the nature of rehabilitation services provided to less severely brain injured children admitted to other hospitals.

**4.2.6 Older People.** After initial resuscitation and treatment in the neurosurgical unit, or more commonly general and orthopaedic surgical wards in local acute hospitals, patients either return home or may be admitted to a stroke unit under the care of a stroke physician or geriatrician. A few are admitted to RABIU (See the graph at paragraph 4.2.3 for the profile of RABIU admissions). Two acute services for older people were visited, in Daisy Hill Hospital in Newry and Ulster Hospital, Dundonald.

Currently, increased resources have been allocated to offer acute stroke thrombolysis. This is likely to increase the number of stroke survivors slightly, thus compounding the discharge pressure on stroke services, which already appears to be intense.

The review team was struck by the low clinical profile of older patients with traumatic brain injury within the acute geriatric service. The senior clinicians we spoke to indicated that they were aware of no more than one or two such patients requiring their expertise each month, and they were rarely consulted by surgical teams requesting transfer of these patients for rehabilitation.

Once admitted to stroke units in particular, older ATBI patients are treated by multidisciplinary teams, who engage in weekly goal-setting, led by the Stroke or Care of the Elderly Physician. The therapist patient ratio is considerably less favourable than in the RABIU, therefore treatment programmes are proportionately less intense. Although it is likely that the potential for rehabilitation of these patients is less and that they may not be suitable for intense rehabilitation. However, the accommodation within these units is not particularly geared to the needs of people with disturbed behaviour and there are no clinical psychologists attached to the teams, although we acknowledge the recently published stroke strategy aims to address – among other priorities – the need to secure appropriate psychological input to stroke services.

## **4.3 Communitiy Based Rehabilitation**

### **4.3.1 General**

In all districts, there are Community Brain Injury Teams (CBIRTs) led by clinical psychologists. They appear to be very well led and effective. The teams have developed in response to local pressures and commissioning initiatives but not as part of a strategic plan. Thus they differ in composition, admission and discharge criteria, resourcing and workload (**table 4.5**). This is likely to be giving rise to inequities in service provision between districts but since data collection is not standardised there is a lack of commonly used outcome data on which to base an estimate of this effect.

There appears to be a systemic divide between community services for people with brain injury, stroke and other causes of neurological disability even where the rehabilitation and support needs of individuals is similar to those with ABI. We are not in a position to comment further on current provision for those whose rehabilitation needs arise from stroke or other causes of neurological disability.

Only two teams have any access to a specialist in Rehabilitation Medicine – the Southern and Northern Trust teams who have sessional inputs. However, teams can refer on a case by case basis to RABIU based rehabilitation medicine or to Elderly Care Medicine services. Only Belfast and South Eastern Teams (Eastern Board area) have access to neuro-psychiatry sessional inputs as neuro-psychiatry is only commissioned in this Board. All but one team (South Eastern) is co-ordinated through neuro- and clinical psychology where a nurse is the professional background of the manager. The presence of a social worker in each team enhances its effectiveness. They liaise well with community services but not all have accepted responsibility for promoting vocational rehabilitation. All teams reported a key focus on supporting clients and their families to cope and adjust to community living, including the management of the often global impacts of an acquired brain injury.

All report difficulties with onward placement into respite, day centre and vocational rehabilitation services and this impedes throughput to a varying extent. In case finding it emerged that all teams have found a significant number of adults with ATBI who were initially discharged from hospital (often directly from surgical wards) without rehabilitation needs having been identified but who then ran into difficulties in the community over the next 6 - 12 months.

### **4.3.2 Adult Services**

A profiled composition of adult community staff teams by Trust area, including professions, activity caseload and length of service is detailed in **table 4.5** below.

#### **Belfast Trust (North and West/South and East)**

The two Belfast teams cover the two former legacy Trust areas - North and West Belfast and South and East Belfast. Both are led by a neuropsychologist and have approximately similar staffing profiles. The South and East Team is based at the Maine/Mourne nucleus of brain injury services. Interventions by both teams include intermittent programmed multidisciplinary rehabilitation, access to vocational and training opportunities and support for community living. A key worker system is operational, with weekly multidisciplinary meetings and case reviews with families.

**South Eastern Trust (Down Lisburn/UCHT)**

The South Eastern Trust has two community brain injury teams covering legacy Trust areas of the Ulster Community and Hospitals Trust and Down Lisburn areas. Both are well established teams with a strong neuropsychology membership but with an overarching Rehabilitation Services Manager who also has responsibility for an inpatient facility – Thompson House Hospital (see 4.2.2). The team offers access to vocational, employment rehabilitation and support for community living options. Again, a key worker system is in operation, with weekly multidisciplinary case reviews with families and social workers. The Down Lisburn team has held CARF accreditation for home and community rehabilitation since 2003. Both teams provide information on outcomes achieved.

Table 4.5 Staff profile and intervention statistics, Adult Community Brain Injury Teams – August 2008.

STAFF Profile by Grade and w.t.e.	N&W BHSC T	S&E BHSC T	Mourn e BHSC T	Total	NHSCT	SHSCT	SEHSCT (2 teams)	WHSCT
Team Co-ordinator/ Lead (Neuro-psychology)	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				
<b>TOTAL STAFF WTE</b>	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/a ctive	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

### **Northern Trust**

The Northern Brain Injury Team offers services across three legacy trusts areas: Causeway, Homefirst and United Hospitals. As can be seen from the profile in **table 4.5**, the team has access to a Consultant in Rehabilitation Medicine for one session per week. It is a well established and staffed team (the largest in Northern Ireland and led by a neuropsychologist) that has been operating across these legacy Trust areas for a significant period of time.

One variant on admission criteria is that this team sees clients generally within a five year post injury timeframe. The Northern Team also specifically links with 2 w.t.e Social Workers located across 4 generic Physical Disability Teams as specialist links in brain injury. They also have an outreach nurse involved in case finding including in acute hospitals in the Northern area. Vocational and social reintegration are a feature of this service which is for over 18s who require sustained long term and post acute rehabilitation both independently and in partnership with voluntary sector providers.

### **Southern Trust**

The team offers a service across three legacy trust localities: Armagh and Dungannon, Craigavon and Banbridge and Newry and Mourne. As the smallest community team this also has neuro-psychology leadership but the team currently has a focus on traumatic brain injury only, with clients over 18 years. They have also access to a Rehabilitation Medicine consultant. They offer post-acute or intermittent rehabilitation focussing on vocational, employment rehabilitation and support for community living. Again a key worker system is in operation with weekly multidisciplinary team meetings. The Southern Trust area team complement in **table 4.5**, has been amended to reflect the stated intention to recruit a higher grade of staff to the 0.6 w.t.e current senior vacancy. Onward referral tends to be to generic disability services where they have three whole time equivalent brain injury support workers located.

### **Western Trust**

The Western Trust community brain injury team is split between two legacy sites 60 miles apart - Foyle and Sperrin Lakeland. The team is led by a neuropsychologist, and they use a case management model with 3 brain injury social workers working with clients and care managing rather than referring back through to generic physical disability services. The Team provides a comprehensive assessment service to those referred to it, but they report that their options for onward referral and continuing support are limited and this is particularly the case in the south western part of the Trust.

#### **4.3.3 Children and Adolescents**

Inpatient services respond well but report extreme pressure with limited access to services such as psychology and speech and language therapy as well as a sub optimal environment. Children are not followed up by the paediatric neurology service once they are discharged, as there are limited resources to allow for this.

There are no community based rehabilitation services specific to children with traumatic brain injury or indeed specialist paediatric rehabilitation as such. With respect to children, those aged 15 and under may occasionally receive help from RABIU as outpatients but the youngest patient we heard of, exceptionally, was aged 13. Currently, paediatric neurology offers what rehabilitation is currently provided and are seeking the appointment of a dual trained neurologist and rehabilitation specialist.

We were told that, despite this, liaison with educational psychologists within the school system is generally good within the Belfast area. We have not explored this element of the service across the province, which is a task that needs to be

undertaken as important part of the strategic monitoring of brain injury rehabilitation for children.

Apart from these few individual practitioners, the only designated community support services for children with ATBI are provided by the Child Brain Injury Trust. The situation for children is thus less favourable than the situation for adults with ATBI but it would appear that no data are currently being collected to monitor the effects of this relative lack of provision through community teams for children. However, it is possible that paediatric services could provide services.

#### **4.3.4 *Older people***

We were told that, in general, elderly patients recovering from head injury are rarely followed up as outpatients and until recently were ineligible for input from some community brain injury rehabilitation teams. The Northern Trust CBIRT rehabilitation team used to provide input to appropriate patients with stroke who were aged under 65, but since the team was instructed to allow access to head injured people over the age of 65 it has chosen to focus its resources on ATBI and this may impact on the priority given to younger people with stroke.

#### **4.3.5 *Community Teams – Stroke***

There are community based teams for stroke rehabilitation in each Trust. The two teams that responded to the review are linked with a stroke service and operate as outreach teams from the local hospital with links to the local geriatrician. They are less geared to active rehabilitation of the kind needed by younger adults and do not liaise with vocational or educational services. Clinical psychology is not included. As noted elsewhere, we acknowledge that the Stroke Strategy for Northern Ireland will seek to address psychology input to these services.

#### **4.3.6 *Community Teams – Physical Disability***

There are generic physical disability/rehabilitation teams for people of all ages that may provide non specialist help to some ATBI patients, particularly if their needs have been identified as principally physical in nature. However, physical impairment caused by ATBI is almost always associated with significant and symptomatic cognitive impairments. We have seen no statistics of the actual numbers of ATBI patients seen by these services.

### **4.4 *Voluntary Sector Rehabilitation***

There are a number of independent and voluntary organisations active in acquired brain injury in Northern Ireland and providing services for its citizens elsewhere. A small number of patients are transferred to specialist independent facilities in England, usually for programmes to address challenging behaviour. These services did not form part of our programme of visits and submissions and are not, therefore, discussed in the following paragraphs which restrict themselves to services provided within Northern Ireland.

#### **4.4.1** The voluntary sector in Northern Ireland is the primary provider of the following key services:

- Residential and supported living options
- Prevocational and vocational rehabilitation
- Enhanced day support and social reintegration

There are two types of voluntary sector organisation active in brain injury in Northern Ireland – those whose main business is service provision under contracts – often held with more than one government department - and those who engage in voluntary activity, in particular peer/carer support, advocacy and awareness-raising.

#### **4.4.2 Service providers**

##### Cedar Foundation; Leonard Cheshire; Reconnect and Praxis

As with the statutory provision, the range of services has arisen from initiatives taken by the voluntary sector in response to need/special interest – not in the context of a defined strategy.

Since the development of Community Brain Injury Teams these have become – in all cases – a primary source for referral for these independent providers and for the local coherence of their activities within any broader care plan for an individual.

The voluntary sector providers, therefore, get a degree of professional support and oversight by clinical services. The Community Brain Injury Teams – without the presence of these voluntary sector providers – would have few options for onward referral of their clients or the delivery of meaningful care plans for them.

The source of funding of the voluntary sector can dictate the type of client suitable for the service that is offered.

The team met with those voluntary organisations providing services regionally or across more than one board area.

##### Cedar

The Cedar Foundation is the single largest provider of services for people with brain injury in the voluntary sector. Some of its main programmes are funded substantially by the European Community through, and by, the Department of Employment and Learning. This creates the need to focus within these particular programmes of care on clients for whom a vocational outcome can be achieved and these programmes tend, therefore, to be best suited to clients with a reasonable level of recovery from their injury.

Cedar Foundation programmes include:

- Vocational Rehabilitation
- Floating Support
- Residential
- Supported Living
- Children's Outlook
- Transitional Support for Young People

Some of these services are truly regional in that they are provided in each Trust area – vocational rehabilitation, for example. However, others are provided only in certain areas – floating support being available only in Belfast, Newry/Mourne and Lisburn. Residential and supported living options are available only in Belfast and Lisburn – although residents of other areas may exceptionally access them – the priority is for residents of these areas.

## **Reconnect**

Reconnect provides a prevocational training service to brain injured clients at a dedicated facility in the Castlereagh Hills outside Belfast. It is funded by Health and Social Care and this is reflected in the client group, many of whom require long term and slow stream rehabilitation and some of whom exhibit challenging behaviours.

This service is targeted at people who have typically higher needs than those who could benefit from the vocational training services offered through employment streams of funding.

The service operates through referrals from Community Brain Injury Teams in the Eastern area of Northern Ireland and these teams are active in the development and delivery of services to clients by Reconnect in the context of their care planning.

The centre itself is in a rural setting and able to offer training in practical skills such as horticulture as well as basic skills such as literacy and numeracy. Its relative solitude offers a calm environment appropriate to the specific needs of brain injured people. However, because the service is centre based it is accessible only to those people who live within reasonable travelling distance.

## **Leonard Cheshire**

The Leonard Cheshire organisation provides residential, modular day support and floating support to people with brain injury within the Western Health and Social Care Trust.

The Leonard Cheshire organisation has the capacity to provide for people with relatively high levels of need, including challenging behaviour. Its activity in the area of brain injury was very much informed by demand for services by people who were otherwise difficult to place and, therefore, its services may tend to focus on those clients with a higher level of disability and fewer options for independent living.

Like other independent providers, it operates in close collaboration with the Community Brain Injury Team who provide referrals, and clinical support.

## **Praxis Healthcare Group**

Praxis Healthcare group are a major provider of services within Northern Ireland and beyond including learning disability, mental health issues and challenging behaviour. Their client group includes people with acquired brain injury as part of other more generic projects and schemes and they are currently developing proposals for the provision of a six bedded unit for people with challenging behaviour following brain injury.

## **Jigsaw**

Jigsaw was founded in 1990, and is a registered charity. It provides support and assistance to people with brain injuries from the greater Belfast and North Down areas. Jigsaw offers support to approximately 145 individuals per week, and provides respite to approximately 125 carers per week. Jigsaw has a strong cross-community ethos, and focuses on integrating people with brain injuries into local and community services, resources and leisure facilities.

While the team did not meet with Jigsaw, the contribution of this organisation to the overall pattern of service is noted.

#### **4.4.3 Voluntary Activity**

##### **Headway; The Child Brain Injury Trust; Northern Ireland Traumatic Brain Injury Forum**

###### **Headway**

There are five Headway groups in Northern Ireland of whom one – Headway Belfast – provides some social reintegration, family support and counselling services. In the main, however, Headway can be characterised as providing peer support for brain-injured people and for carers, advice and information for those newly affected by brain injury, awareness raising and social events.

One of the groups is newly formed and each group is to a degree limited by scant resources and reliance on individual volunteers. Headway in Northern Ireland does not display the same level of development as in some parts of England and there is in all probability potential for further development of the type of service they offer, particularly given the stated need for additional information services and family support expressed by service users and by carers.

One service particularly valued by users, for example, was the STAR programme commissioned by EHSSB and offered currently through Headway Belfast only primarily for the purpose of social reintegration. In addition, Headway maintains a presence at RABIU for the purposes of providing immediate support to carers of people who are newly brain injured. Headway has maintained a physical presence in RABIU and, before that in the Joss Cardwell Centre and Forster Green Hospital for many years, and continues to offer support to families and carers from that location. It should also be noted that the STAR project is directly commissioned by the EHSSB.

###### **The Child Brain Injury Trust**

The Child Brain Injury Trust is rapidly developing as an organisation providing awareness-raising, family support to 25 families across Northern Ireland, advocacy and training within schools in support of brain injured children in mainstream education. A social programme is part of its work also.

The importance of this service in the context of the lack of provision for brain injured children through statutory services should be noted. Their activity in schools is of particular importance given the need for dedicated effort to address the specific needs of the brain injured child.

###### **Northern Ireland Traumatic Brain Injury Forum**

The Northern Ireland Traumatic Brain Injury Forum is a membership organisation, volunteer run and without resources that exists to raise awareness of needs within brain injury and to publish papers on aspects of service provision to this end. Its members include the organisations active in brain injury, clinical professionals, carers and service users.

## **4.5 Users, Families and Carers**

The team met with families and carers on four occasions, three of which were organised through the Northern Ireland Traumatic Brain Injury Forum. In addition, the team held a meeting with a small group of service users and met with representatives of Headway in Northern Ireland, which included carers.

The experiences shared with us ranged from a 5 to 20 year period since injury. In the large majority of cases, the injury had been moderate to severe, necessitating inpatient care and rehabilitation and referral, on discharge, to long term support from specialist inpatient care in a facility outside Northern Ireland to care at home with support.

The following outlines the key themes emerging from these engagements.

### **4.5.1 Carers**

#### **a. Advocacy**

It was the near universal experience of carers that, over the period of care and rehabilitation of their relative they had been required to become assertive and expert advocates, reporting lives composed not only of fulfilling the daily care needs of their relative but seeking access to and maintenance of an acceptable level of service for them.

#### **b. Care Planning**

Many reported the need to be particularly active at transitional stages in the life or care of the individual – for example, as they progressed through education into adulthood, as they completed each course of training in the voluntary sector or as they exhausted options for care – this last particularly for those with relatives who exhibited challenging behavior.

Two carers reported being advised to go around usual processes of referral in order to make progress. Other carers reported an increasing expectation of them to advise and suggest options for their family member – particularly by General Practitioners and generic Social Workers.

#### **c. Isolation**

Many carers reported the breakdown of other family relationships and the loss of working and social life consequent to the new requirement to adjust to the complex needs of a brain injured family member. The effect of this widespread isolation and the demands of care led to a reported need for support to be provided to them as carers, notwithstanding the needs of their relative from the point of injury onward and including improved communication from services generally, early information on brain injury and its consequences and access to respite care.

#### **d. Service Needs**

Most carers were concerned primarily that their relative should be better enabled to live as independently and in as fulfilling a way as possible. Access to services that allowed their relative to socialise and enjoy themselves – outside the objectives driven realm of rehabilitation, service provision and training and education was reported as a current gap in services as was options for supported living. Age was a factor in this desire for independence. Parents of younger adults wished to see their children progress as far as possible through the normal stages of life. Older carers expressed concern at the long term care for their relative should they become unable to continue to provide care for them.

#### **4.5.2 Users**

The small group of users with which we met expressed concern for their carers and the isolation they experienced from the initial period of hospitalisation. They had – as might be expected – scant recall of the earliest phases of their recovery and did not, therefore, express views around this area of care. They did report, however, a period of hiatus between their discharge from inpatient care until they accessed various types of community support through referrals from Community Brain Injury Teams.

All expressed appreciation of the work, not only of these teams, but of the community-based independent sector services in particular and the programmes they delivered for social reintegration and vocational rehabilitation.

## **5.0 RECOMMENDATIONS**

### **5.1 Commissioning**

1. A regional managed clinical network for acquired traumatic brain injury 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.

### **5.2 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 out-patient 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.

### **5.3 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 childrens' 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.

### **5.4 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.

Table 4.6: *Prioritised recommendations*

Reference number	Objective	Priority
5.1.1.	A regional managed clinical network for acquired traumatic brain injury should be established	1
5.1.2.	Needs assessment of older people and children with acquired traumatic brain injury should be undertaken.	2
5.1.3.	The commissioning process should recognise quality of life issues, and prioritize services for this.	2
5.1.4.	The alternatives to the referral of patients overseas should be explored as a matter of priority.	3
5.1.5.	A comprehensive family support service should be commissioned.	1
5.2.1.	Comprehensive rehabilitation care pathways should be created for children, adults and for older people with a common co-ordinating lead.	2
5.2.2.	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.	2
5.2.3.	The Regional Acquired Brain Injury Unit should be developed as a resource for training, education and research in brain injury.	2
5.2.4.	Appropriate environments should be provided within acute hospitals for people with brain injury.	3
5.2.5.	Consideration should be given to developing 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.	2
5.2.6.	Spruce House should be developed as a key sub-regional inpatient and out-patient facility.	2
5.2.7.	Additional input by a Consultant in Rehabilitation Medicine should be provided to services at Thompson House Hospital and at Spruce House, Altnagelvin Hospital.	1
5.2.8.	Alternative accommodation should be developed for the regional inpatient service for people with challenging behaviour. Neuropsychiatric provision and support should be enhanced across the ATBI network to provide for this.	2
5.2.9.	Appropriate accommodation should be provided for children with brain injury receiving inpatient rehabilitation.	3
5.2.10.	Clinical and professional staff resources should be provided appropriate to meet the inpatient rehabilitation needs of children.	1
5.3.1.	Community Brain Injury Teams in each Trust area should be maintained and staff profiles streamlined.	2
5.3.2.	A community-based regional service should be established to address the rehabilitation needs of children, appropriately linked to inpatient and outpatient childrens' rehabilitation services and to the wider network of brain injury services.	1
5.3.3.	The development of supported living and residential options should be sponsored for people with challenging behaviours.	3
5.3.4.	Nursing home places should be developed for people who are in minimally responsive and persistent vegetative states – including those with a tracheostomy.	2
5.3.5.	The development of age-appropriate respite for people with brain injury living with carers should be supported.	3
5.4.1.	Existing services for pre-vocational and vocational rehabilitation and for social re-integration should be maintained.	3
Reference number	Objective	Priority

5.4.2.	Services for people with brain injury that are social in their nature and benefits should be strengthened.	2
5.4.3.	A forum for service users and carers should be developed,	1

Key:

- 1- Immediate to short term (up to 1 year)
- 2- Medium term (up to 2/3 years)
- 3- Long term (up to 5 years)

## **APPENDIX A**

### **Terms of Reference**

1. To review the nature, capacity and effectiveness of the services currently provided in Northern Ireland for the assessment, treatment and rehabilitation of people of all ages and genders who have suffered an acquired traumatic brain injury.
2. To consider provision in the context of equality and human rights legislation
3. To take into account good practice from the National Service Framework on Long Term Conditions.
4. The Review will draw on guidelines from professional bodies, consider examples of good practice and make recommendations on how traumatic brain injury services should be organised and provided to achieve the optimum outcomes for patients.
5. The services provided to people who present with a brain injury at the acute stage will not be reviewed as part of this work. However, the Review will be informed by and will take into account the Department's Stroke Strategy and Review of Trauma Services when it exams the patient journey in full.
6. The review will be completed by 30 September 2008.

The outputs expected from the Review are:

- Regular feedback to the Department as the Review progresses;
- A mapping of current provision and an identification of gaps including any age or gender specific gaps;
- A mapping of the patient journey and referral pathways;
- Recommendations in response to the Terms of Reference.

#### **Notes:**

Community Brain Injury Teams are a vital part of rehabilitation and there should be a seamless connection between them and hospitals. These teams are not long established and the Review should take a view on their further development.

The definition of a Traumatic Brain Injury is an injury which results from an external force such as a road traffic accident, fall or sports injury. An Acquired Brain Injury is any injury to the brain that results in damage to living tissue of the brain causing permanent or temporary changes to the structure of the brain. It includes: Accident; Assault; Fall; Stroke; Tumour/Cyst; Anoxia resulting from Cerebral Vascular Incident, drowning, strangulation etc; Haemorrhage; Aneurism; Encephalitis / Meningitis.

## **APPENDIX B**

### *Short biographies of review team members*

#### **Richard Dixon**

Richard Dixon has senior management experience in Health and Social Care and in the Voluntary Sector as Director of a Northern Ireland charity for people with acquired brain injury. At present, he is the Chief Officer of the Eastern Health and Social Services Council, an independent body with responsibility for representing the views of patients and the public on services in the Eastern part of Northern Ireland.

#### **Professor Lindsay McLellan**

Professor McLellan was appointed as Senior Lecturer and Consultant neurologist at the University of Southampton in 1977 and held the Europe Chair of Rehabilitation from 1984 until retirement in 2000. He has undertaken research and published extensively in the field of neurological disability and rehabilitation and has a particular interest in Traumatic Head Injury and its Rehabilitation. He was also an advisor to the Welsh Affairs Committee and the Health Select committee of the House of Commons in their reviews of Head Injury services in Wales and England. He is a member of the European Academy of Rehabilitation Medicine and continues to undertake regular clinical work at the Peartree House Rehabilitation Centre in Southampton.

#### **Dr Jacinta Morgan**

Dr Morgan is a Consultant in Rehabilitation Medicine in Dublin, at the National Rehabilitation and Beaumont Hospitals, and is one of four medical consultants providing a national rehabilitation service for adult patients after acquired brain injury. Prior to that, she worked at the Royal Cornwall Hospitals Trust, Cornwall for 9 years as a Consultant in Stroke and Rehabilitation Medicine. During her tenure there, she provided clinical leadership in the development of a county-wide stroke service, and enhancement of services for patients after traumatic brain injury, through the medium of collaborative multi-agency reviews. In 2003/4, she led a review of inpatient neurorehabilitation services in the South West Peninsula.

## APPENDIX C

### N.IRELAND BRAIN INJURY SERVICES REVIEW

#### SURVEY OF IN –PATIENT AND COMMUNITY SERVICES

#### 1. Demographic data and service configuration in relation to April '07-March'08

1.1 What is the catchment population of your service? (geographical area and number)

1.2 Does your organisation provide or have current access to services designated (either formally or informally) for rehabilitation after a brain injury?

1.3 Where are they located? How many places currently do you provide?  
Please tick all that apply.

(a) Type of unit/service	(b) Number of places	(c) Lead Clinician by profession
General Rehabilitation unit		
Specialist rehabilitation unit e.g stroke /fracture		
Community Rehabilitation Services		
Voluntary Sector Provision		
Out of area/region specialist provision		

1.4 Please ESTIMATE the age and gender profile of patients admitted to these services OVER THE PAST YEAR with the following diagnoses/characteristics:

Diagnoses / characteristics.	65-75		75-85		85+	
	M	F	M	F	M	F
Traumatic brain injury (inc. hypoxic-ischaemic)						
Complex Stroke / sub-arachnoid haemorrhage						
Patients in a low awareness state after TBI						
Patients with significant behavioural difficulties after TBI						
Ventilator-dependent patients after TBI						

1.5 What is the average LENGTH OF SERVICE in days for service users?

1.6 Do you maintain your own demographic and clinical database? **YES** **NO**

1.7 Please ESTIMATE the number of referrals received OVER THE LAST YEAR and the source of referral.

Source	Number
Own acute setting - general ward	
Neuro-surgery - regional	
Other acute setting	
Other Clinician	
G.P.	

## 2. Staffing

Please indicate the number of staff working in your rehabilitation service

Profession		WTE	
Dedicated Rehabilitation Manager			
Medicine	Rehabilitation Physician		
	Care of the Elderly Physician		
	Consultant Psychiatrist		
	Staff Grade/Associate Specialist		
	Specialist Registrar		
	SHO/HO		
Rehabilitation nursing	Consultant or Specialist		
	Band 7		
	Band 5		
	Band 2/3		
Neuropsychology/ Psychology	Consultant		
	Principal		
Social Work	Senior Practitioner – Band 7		
	Social Worker – Band 6		
Dietitian			
Other professional support staff e.g.: Rehabilitation Assistant Community Support Worker			
<b>Allied health professional</b>		<b>WTE total</b>	<b>WTE specialist trained</b>
Physiotherapy	Band 7		
	Band 6		
	Band 5		
	Assistant Band 2/3		
Occupational therapy	Band 7		
	Band 6		
	Band 5		
	Assistant Band 2/3		
Speech and Language therapy	Band 8		
	Band 7		
	Band 6		

## 3. Admission and discharge procedure; process of rehabilitation

3.1 What are the reasons for admission to your service? (tick all that apply)

Single incident brain injury:	Rehabilitation	
	Slow-stream rehabilitation	
Intermittent programmed rehabilitation		
Emergency admission in response to crisis /complex discharge etc		
Respite care		
Community rehabilitation /living support		

### 3.2 Pre-admission assessment

Do you have written criteria describing service users suitable for admission/ acceptance to programme?  
{If so please detail}

Who carries out admission assessment?

What is the average wait in days for admission to your service over LAST YEAR?

### 3.3 Process of rehabilitation

Do you assign a key worker (not primary nurse) to service users on admission?  
YES NO

Do you use care pathways or collaborative documents on your unit? YES NO

How often does the multidisciplinary team meet for discussion and goal setting?

Do you arrange case reviews with patients, carers and social care staff?  
YES NO

If so, how often?

### 3.4 Outcome measurement

Do you routinely record outcome measures on your patients? YES NO  
If yes, please list them.

### 3.5 Discharge process

How many users were discharged from your service over the last year?

To whom did you refer discharged services users?

To where did you discharge?

<b>Location</b>	<b>Male</b>	<b>Female</b>
<b>Own Home</b>		
<b>Supported living with care</b>		
<b>Specialist nursing /residential</b>		
<b>Other [please specify</b>		

How are complex discharges organised and documented?

### **NAME OF LEAD CLINICIAN:**

PLEASE RETURN AT YOUR EARLIEST CONVENIENCE AS THIS INFORMATION WILL BE USED BY THE REVIEW TEAM TO ASSIST IN MAPPING THE REVIEW PROCESS.

## APPENDIX D

### Schedule of visits

12/05/2008	Stormont Hotel	Family of Mr Hanratty Four Board Commissioners
19/05/2008	Thompson House Hospital Lisburn, South Eastern Trust	Facility 2 Community Brain Injury Teams
23/05/2008	Maine Villa – Knockbracken Belfast Trust	Facility 2 Community Brain Injury Teams
23/06/2008	Independent Service Providers Castle Buildings	Cedar Foundation Leonard Cheshire Headway Reconnect Praxis
27/06/2008	EHSSC Belfast	Children’s Brain Injury Trust Southern Community Brain Injury Team Northern Community Brain Injury Team
30/06/2008	Castle Buildings R.V.H. Belfast	N.I. Traumatic Brain Injury Forum Regional Neuro –Surgery
04/07/2008	Musgrave Park Belfast	Regional Acquired Brain Injury Unit
07/07/2008	Londonderry	Spruce House, Altnagelvin Western Community Brain Injury Team
18/07/2008	Dundonald	Stroke Rehabilitation Ulster Hospital
25/07/2008	Newry	Stroke Rehabilitation Daisy Hill Hospital Newry
22/08/2008	Belfast	Carer Consultation Service User Consultation
29/08/2008	Belfast	Neurology/ Rehabilitation Childrens Hospital

## APPENDIX E

### References

1. *The National Service Framework for Long-term Conditions*. DH Long-term Conditions Team. 10 March 2005
2. *Third report, House of Commons Health Committee 2001*. Head injury : rehabilitation. <http://www.publications.parliament.uk/pa/cm200001/cmselect/cmhealth/307/30704.htm>
3. *Report of the working party on the management of patients with head injuries*. Royal College of Surgeons, London, 1999
4. *Medical Rehabilitation for people with physical and complex disabilities*, Marks L et al, Royal College of Physicians, London May 2000
5. *Rehabilitation following acquired brain injury: national clinical guidelines* (Ed. L. Turner-Stokes). London, Royal College of Physicians, British Society of Rehabilitation Medicine, 2003)
6. *Vocational assessment after acquired brain injury: Inter-agency guidelines*. Clinical Effectiveness and Evaluation Unit, Royal College of Physicians , London, 2004)

### Relevant guidelines from previous UK Government and Department of Health Reviews of service for people with Traumatic Brain Injury

Refs:

*Welsh Affairs Committee (1995) House of Commons Health Select Committee (2001) Mapping Survey of Social Services Provision for Adults aged 16 Years and Over with Acquired Brain Injury and their Carers in England, UKABIF, 2004)*

The following recommendations and observations from the above appear relevant to the situation today in Northern Ireland

2. Without the application of specific procedures some patients (at all ages) are likely to be discharged from acute hospitals having had a head injury with persisting or cognitive impairments that have not been diagnosed.
3. People with suspected TBI should be assessed by specialist staff. Those with TBI must be nursed in an appropriate location which is quiet and allows continual observation. Unless awaiting or recovering from surgery, patients with ABI should not be nursed in General Surgery or Orthopaedic wards.
4. Head injured inpatients should be transferred to a rehabilitation ward or unit as soon as they are medically and surgically stable
5. A case management or case co-ordinator system is necessary to guide and inform patients with head injury throughout the care pathway. Pathways should enable passage through the system without hold-ups so as to ensure the optimal use of resources at each point in the pathway.
6. Accurate information and support must be given to families to facilitate their involvement in the patients' recovery and rehabilitation

7. The cognitive and behavioural consequences of ATBI demand more specialist input than is currently available, particularly from clinical psychology and speech and language therapy.
8. The Department of Health should help charitable organisations where they are providing core services. Statutory services should recognise the contribution of the independent sector and collaborate actively with it to provide the best possible service for patients.
9. Intermediate care cannot be relied upon to provide comprehensive rehabilitation after brain injury.