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**Quality Improvement**  
Authority

The Regulation and Quality Improvement Authority

Review of Brain Injury Services in Northern Ireland

September 2015

Assurance, Challenge and Improvement in Health and Social Care

[www.rqia.org.uk](http://www.rqia.org.uk)



## **The Regulation and Quality Improvement Authority**

The Regulation and Quality Improvement Authority (RQIA) is the independent body responsible for regulating and inspecting the quality and availability of health and social care (HSC) services in Northern Ireland. RQIA's reviews aim to identify best practice, to highlight gaps or shortfalls in services requiring improvement and to protect the public interest. Our reviews are carried out by teams of independent assessors, who are either experienced practitioners or experts by experience. Our reports are submitted to the Minister for Health, Social Services and Public Safety, and are available on our website at [www.rqia.org.uk](http://www.rqia.org.uk).

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

Richard Dixon	Complaints Services Manager, Patient and Client Council
Shona Mackie	Paediatric Neurology Nurse Specialist, University Hospital Southampton NHS Foundation Trust
Jane McNeil	Consultant Clinical Neuropsychologist, Solent NHS Trust
Sean Murphy	RQIA Lay Reviewer
Dr Danny Smith	Specialist Registrar in Rehabilitation Medicine, Northern Ireland Medical and Dental Training Agency
Sallyann Smith	Clinical Manager Neurological Rehabilitation Service and Clinical Specialist Physiotherapist, Solent NHS Trust
Hall Graham	Head of Programme, Reviews and Primary Care Advisor, RQIA
Dean McAllister	Project Administrator - RQIA
Jim McIlroy	Project Manager - RQIA

RQIA thanks the Cedar Foundation, Headway, Reconnect, Brain Injury Matters, Brain Injury Foundation and the Child Brain Injury Trust for their assistance engaging with people living with brain injury, their carers, and family members during the review.

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## **Executive Summary**

This report outlines the findings from the review of brain injury services, and proposes recommendations for improvement to these services.

The adult brain injury services provided by the health and social care trusts are predominantly community based. With the exception of the Belfast Health and Social Care Trust (Belfast Trust), there were limited specific services within the acute hospital setting, although post-acute inpatient rehabilitation is provided.

Trusts' brain injury teams were working independently, with a lack of strategic direction for the service across Northern Ireland. More collaborate working arrangements need to be established to implement service improvement, share innovation and reinforce service standards on a regional basis.

Community brain injury teams and rehabilitation units had embraced the 'Brain Injury: Service Standards and Quality Indicators'; however, there was limited evidence of their application within the acute hospital setting.

Various protocols, procedures and operational policies specific to brain injury had been developed, although several documents outlined within the brain injury standards were not in place.

Systems were in place for the identification of patients with a traumatic brain injury. The referral of patients with a mild brain injury was not consistent for all. Patients admitted to hospital were only receiving general therapeutic interventions of limited intensity. Post-acute inpatient rehabilitation was provided by dedicated, skilled and enthusiastic staff, trained in the management of patients with a brain injury. Care was provided on a multidisciplinary basis.

Community brain injury teams were enthusiastic and dedicated to providing care. The degree of specialist expertise among all disciplines was evident. The teams tried to maximise the functional ability of patients and keep them engaged until rehabilitation goals were achieved. Information about brain injury was available, but trusts need to review how and when it is delivered.

Working relationships with various statutory, voluntary and charitable organisations had been developed. The number of relevant organisations was increasing, and a suitable strategy for engaging them should be identified.

Trusts did not provide specific accommodation for people living with a brain injury, but worked with other organisations to provide the most suitable accommodation for them. Often younger patients were placed in unsuitable environments, such as nursing homes, where there are limited social opportunities.

A distinct gap across Northern Ireland was in relation to the provision of appropriate treatment facilities for adults with extremely challenging behaviour, or with complex needs. This needs to be reviewed.

Access to mental health services was difficult, with long waiting times reported and limited collaboration. Particular challenges were identified in relation to drug and alcohol addiction services.

There were no specific children's brain injury services, with children being cared for within the relevant specialty of children's services. This model of care is consistent with most services in the United Kingdom.

It was difficult to identify the drivers for providing the strategic direction, or how service improvement specific to brain injury could be initiated. Within children's services there were no specific policies, procedures or protocols that aligned to the brain injury standards; the brain injury care pathway for children and young people was the only specific document.

Key members of staff were identified in each trust who had taken a particular interest in children's brain injury, and their drive and enthusiasm was the impetus for making a difference in the level of care being provided.

There are no dedicated facilities for children's inpatient rehabilitation or post-acute inpatient rehabilitation in Northern Ireland. The only service for children's inpatient rehabilitation is within the Belfast Trust.

Paul Ward within the Royal Belfast Hospital for Sick Children was highlighted as not being a suitable environment for neurology patients. The provision of therapy interventions was also highlighted as an area of concern. Both these areas need to be appropriately addressed within the new children's hospital.

In the community, children are cared for by the general children's community teams; however, they had no specific brain injury skills. Advice and support is available from the children's Acquired Brain Injury Consultation Service.

Overall, good working relationships were reported between the voluntary and charitable organisations and the trusts. These relationships need to be maintained and developed for the benefit children and their families.

Trusts did not provide specific accommodation for children living with a brain injury. Trusts concentrated their efforts to support the care of the child at home.

The provision of an appropriate service for children with extremely challenging behaviour or with complex needs was a significant gap. This needs to be included in the review recommended for adult services.

The report makes 23 recommendations for improvement to brain injury services.

## Section 1 – Introduction

### 1.1 Context for the Review

The brain is vitally important for everything we think and do. It determines what we think, what we do and who we are. Although protected by the skull, the brain can still be easily injured, even if there is no obvious external damage to the head.

Each year in the United Kingdom, as many as 1.4 million people attend emergency departments (EDs) following a head injury<sup>1</sup>. It is estimated that approximately 2,000 people a year in Northern Ireland, sustain and are living with the long-term effects of a brain injury<sup>2</sup>.

An acquired brain injury may be defined as any damage to the brain that is sudden in onset and occurred after birth. It is therefore differentiated from birth injuries, congenital abnormalities and progressive degenerative conditions affecting the central nervous system. Acquired brain injury (ABI) may be the result of:

- Traumatic brain injury - the result of an impact to the head, following for example a sporting injury, a car accident or a fall
- Non-traumatic brain injury – resulting from hypoxic/ ischaemic injury, infections such as meningitis, a stroke or a brain tumour.

Brain injuries can impair mental, physical and emotional abilities and can lead to a lifelong disability. The most common effects can include:

- weakness of limbs and inability to control movement
- difficulty with functional activities such as walking or getting dressed
- fatigue
- changes in behaviour including irritability, behaving impulsively or inappropriately
- difficulty with learning and remembering
- difficulty in processing information
- difficulty with concentration
- emotional difficulties such as anxiety or depression
- language/speech difficulties
- difficulty in organising/planning.
- difficulty with everyday tasks

It is often not possible to accurately predict how much a patient may recover, or how long it may take.

Changes in the personality or behaviour of a person with an acquired brain injury can be particularly difficult for families to cope with. In addition, family

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<sup>1</sup> Estimated number of attendances annually at Emergency Departments as a result of head injuries - <https://www.nice.org.uk/guidance/cg176/resources/guidance-head-injury-pdf>

<sup>2</sup> Estimated number of people who annually sustain a brain injury in Northern Ireland - <http://www.northernireland.gov.uk/news-dhssps-300115-know-the-risks>

members may experience their own adjustment difficulties which may lead to carers suffering from chronic stress.

For a person with an acquired brain injury, being able to achieve goals which maximise independence and increase participation in the community is important. A person with a brain injury may have changed physically, cognitively, behaviourally or socially, and the goals which are set will depend on the extent of these changes. The goals of a child who has developmental, social and educational needs, will of necessity, differ from an older person whose desired outcome may be a return to family and social activities, while retaining as much functional independence as possible.

In 2008, the Minister for Health, Social Services and Public Safety commissioned a Review of Services for People with Acquired Traumatic Brain Injury in Northern Ireland<sup>3</sup>. This was in response to concerns raised regarding the treatment and care of people with traumatic brain injury. The review's remit included the mapping of service provision, highlighting areas of good practice and identifying significant gaps in provision. The review found that there was a sense of isolation of elements of the service and insufficient coordination of care for the commissioning and provision of services. In addition, there was little evidence of the performance management information needed to inform commissioning or strategic planning. It was also noted that there were particular issues regarding how the needs of children and older people with acquired traumatic brain injury were being addressed.

Following the review, a report was published which set out recommendations that identified key steps required to improve services for people with an acquired brain injury. These recommendations informed the development of the Acquired Brain Injury Action Plan<sup>4</sup>, a three year plan to develop services for people with acquired brain injury.

The purpose of the action plan was to provide clear, time-bounded goals, to drive service improvement and to coordinate action in order to improve functional outcomes for patients (regardless of age), their families and carers. The action plan was intended to promote a person centred approach to earlier recognition, diagnosis, treatment, rehabilitation, care and support for people affected by acquired brain injury, but also to provide support for their families and carers.

The Regional Acquired Brain Injury Implementation Group (RABIIG) was established in June 2010, to make improvements to health and social care services provided to users and carers of brain injury services. It was jointly managed by the HSC Board and Public Health Agency, and its membership included representatives from the five HSC trusts, statutory bodies, voluntary organisations, service users, parents and carers.

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<sup>3</sup> Review of Services for People with Acquired Traumatic Brain Injury in Northern Ireland - September 2008 - [http://www.dhsspsni.gov.uk/acquired\\_brain\\_injury\\_review.pdf](http://www.dhsspsni.gov.uk/acquired_brain_injury_review.pdf)

<sup>4</sup> Acquired Brain Injury Action Plan – July 2010 - [http://www.dhsspsni.gov.uk/acquired\\_brain\\_injury\\_action\\_plan\\_-\\_final\\_version\\_-\\_draft\\_as\\_of\\_june\\_2010-2.pdf](http://www.dhsspsni.gov.uk/acquired_brain_injury_action_plan_-_final_version_-_draft_as_of_june_2010-2.pdf)

A key initiative progressed by RABIIG was development of the Brain Injury: Service Standards and Quality Indicators<sup>5</sup> (brain injury standards), in 2011. These standards aimed to improve the care experience for people of all ages who had suffered an acquired brain injury. Both children's and adult services are covered by the standards.

This review forms part of the RQIA 2012- 2015 review programme and was included in the programme as a suggested topic following a period of consultation. In determining the scope of this review, RQIA considered both the action plan and the Brain Injury: Service Standards and Quality Indicators. Rather than limit the review to determining the progress of implementation of the action plan which was published in April 2009, it was considered that reviewing the service against the standards would be more relevant and provide a more comprehensive assessment of the service. RQIA used the brain injury standards, as the basis upon which to assess brain injury services provided by the HSC organisations. The review assessed both children's and adult brain injury services provided by the HSC trusts.

## **1.2 Terms of Reference**

The terms of reference for this review were:

1. To review the acquired brain injury services against the Brain Injury: Service Standards and Quality Indicators.
2. To obtain the views and experiences of service users and carers in relation to acquired brain injury services.
3. To report on the findings, identify areas of good practice and, where appropriate, make recommendations for improvements.

## **1.3 Exclusions**

The review did not focus on other progressive brain illness or congenital brain injuries, or the related services for these, provided by the HSC trusts. Stroke services are not covered within this review, as they were reviewed during 2014, by RQIA<sup>6</sup>.

Circulars, guidance, standards, reviews and reports which are issued during the course of this review were not assessed as part of this review but highlighted for consideration in the future.

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<sup>5</sup> Brain Injury: Service Standards and Quality Indicators - <http://www.hscboard.hscni.net/RABIIG/Pathways/001%20Service%20Standards%20and%20Quality%20Indicators%20-%20PDF%201MB.pdf>

<sup>6</sup> Review of Stroke Services in Northern Ireland – December 2014 - [http://www.rqia.org.uk/cms\\_resources/Review%20of%20Stroke%20Services%20in%20North%20Ireland%20-%20Report%20Dec%202014.pdf](http://www.rqia.org.uk/cms_resources/Review%20of%20Stroke%20Services%20in%20North%20Ireland%20-%20Report%20Dec%202014.pdf)

## **1.4 Review Methodology**

The review methodology was designed to gather information about how the service was complying with the Brain Injury: Service Standards and Quality Indicators. The methodology included the following steps:

1. A review of relevant literature set out the context for the review and identified appropriate lines of enquiry.
2. Questionnaires were completed by the Health and Social Care Board and the trusts, to identify compliance with the Brain Injury: Service Standards and Quality Indicators.
3. Obtaining the views of people living with a brain injury and their carers was a key element of this review. RQIA worked in partnership with the voluntary and charitable organisations for brain injury, to set up focus groups to obtain the views of people living with brain injury and their carers. A total of 109 people living with a brain injury and 66 carers engaged in the process.
4. Validation visits to the Health and Social Care Board and trusts were undertaken, to meet with practitioners and managers working within the brain injury services.
5. The initial findings from the questionnaires, validation visits and focus groups were collated, and the results used to inform this overview report.

## **Section 2 – Findings from the Review**

The review team was asked to assess the HSC Board and trusts against the Brain Injury: Service Standards and Quality Indicators. This report outlines the review team's findings against the brain injury standards, references where appropriate the initial review of brain injury services and proposes recommendations for improvements.

### **2.1 Experiences of People Living with Brain Injury**

An integral part of the review was to obtain the views and experiences of people living with a brain injury, who have used the trusts' brain injury services.

RQIA obtained the views of people living with a brain injury and their carers in a number of ways.

- Focus groups arranged by Brain Injury Matters, Reconnect, Headway, Brain Injury Foundation and the Child Brain Injury Trust
- Focus groups facilitated by the South Eastern and Southern trusts
- Independent engagement by Headway and the Child Brain Injury Trust with a report submitted to RQIA.

A total of 109 people living with a brain injury and 66 carers engaged in the process. The majority of individuals living with a brain injury attending the focus groups had acquired their brain injury within the previous five years, although most had acquired their brain injury within the last two years. Only a small number had acquired their brain injury more than six years ago, which was prior to publication of the Acquired Brain Injury Action Plan. The severity of their conditions ranged from mild to severe.

#### **Initial Brain Injury and Hospital Admission**

During the focus groups, individuals discussed their own personal experiences of brain injury. Each person's experience was individual, and unique to them. The majority of people stated that at the time, they did not know or have any previous understanding or awareness of brain injury.

A common experience recalled by many people, was their lack of memory of the days and sometimes weeks following their brain injury. It was through information provided by family, friends and healthcare staff that they became aware of events following their brain injury.

Some people who had suffered a mild brain injury did not require a stay in hospital and were discharged. Their experiences of care in the acute hospital setting varied considerably. Some advised that the care they had received was very good, while others advised it was not. Many were given basic advice upon discharge, although some were not given any information at all.

People who had suffered a moderate brain injury, were initially treated in the ED and were then usually admitted to a neurosciences ward at some stage during their stay in hospital. Some stated they were admitted to another ward first, as a bed was not available, but they were transferred to a neurosciences ward later. Several people advised of being transferred to another hospital for admission, as the hospital they initially arrived at did not have the facilities to care for them. Several considered that some hospitals did not have proper services to deal with brain injury.

People who had suffered a severe brain injury were transferred to the Belfast Trust for admission and treatment.

Although experiences of initial hospital treatment varied, most people felt improvements could be made within the acute hospital setting, in relation to raising awareness of brain injury, its effects, and the need for appropriate rehabilitation.

On admission, experiences of care provided by wards also varied. Where many people reported positive experiences, with statements about excellent care, some people had more negative experiences. Many people thought that they did not receive enough rehabilitation during their stay in hospital, in particular in relation to speech and language therapy, physiotherapy and occupational therapy.

Many people expressed the view that staff were very helpful; however, they were sometimes too busy to provide proper care. In many of the focus groups, people thought that staffing levels needed to be increased in order to deal with the specific needs of the patients.

### **Regional Acquired Brain Injury Unit**

Many people involved in focus groups had spent time in the Regional Acquired Brain Injury Unit (RABIU). Again, there were stories of both positive and negative experiences in relation to the care they received. However, overall there were more positive experiences.

Many spoke about the excellent care they had received in the RABIU, and they felt that being there had contributed to their improved rehabilitation. People stated that the level of physiotherapy and OT provision was “fantastic”, and praised the staff.

Although most were happy with the care they received in the RABIU, several people advised that their rehabilitation did not last long enough. A few people did have negative experiences in the RABIU. They considered that their rehabilitation did not meet their needs or did not challenge them enough.

### **Discharge**

People expressed differing experiences in relation to their discharge from hospital. Most spoke of their appreciation for members of staff from different

disciplines who were involved in their discharge. Those patients who had more complex discharge needs stated that they had been involved in several discharge planning meetings and sometimes a staggered discharge was utilised.

Many people advised that they had not been involved in any discharge planning meetings, although some stated they had discussed discharge with a physiotherapist and occupational therapist. Some advised they did not have any meetings or discussions prior to discharge.

Many people required care packages to be put in place, often involving modifications to their home, before they could be discharged. While many people remained in hospital until these requirements were put in place, a similar number were discharged without necessary adjustments to their home being completed. A disproportionate number advised that their discharge was delayed due to lengthy waiting lists for various therapy services.

### **Support at Home**

Most focus group participants had engaged the services of Community Brain Injury Teams (CBIT) within their respective trust, although the level of input and support varied considerably. People advised that a referral to a CBIT was not always automatic, and in many cases it was often several weeks or months before a CBIT became involved. Many people stated that it was often by self-referral, or by accident, that they engaged with CBITs.

During the time between discharge and coming into contact with a CBIT, people reported that they were under the care of generic community teams. Everyone stated that they thought these teams were not appropriately trained or had sufficient knowledge of brain injury to deal with their needs.

Everyone who had been under the care of a CBIT, advised that the support and therapy they received was extremely beneficial to their rehabilitation and recovery. They continued to be provided with speech and language, physiotherapy and occupational therapy at home. However, the intensity was considered by them to be less, in comparison to the therapy received in the rehabilitation units. Many people only received therapy once or twice a week; however, they were extremely positive in relation to their community rehabilitation experience, citing the great rapport built up and goals achieved, when working with various allied health professionals.

Several people advised that they had not always received the full complement of therapy they had been allocated. They felt that some therapists merely demonstrated the exercises and left it to family members to practice with the patient. They felt this was not the responsibility of family members.

People expressed concern at the total length of time allocated for therapy. Many advised they only received several weeks of therapy, which could last up to 12 weeks. They did not understand why a 12 week cut-off existed, as recovery and routine was only beginning to be established at that time, at

home. Others advised of receiving therapy over a longer period. Some people had purchased their own physiotherapy in order to continue their rehabilitation at home.

### **Support for family and carers**

The majority of family members and carers that were involved in the focus groups advised that they did not receive as much support as they felt they needed. They stated that psychological support and counselling would have been beneficial to them. Many advised that they were not aware that a clinical psychology service should be available. Many family members felt that they would have benefited from counselling, in relation to coming to terms with living with, and providing support to, individuals living with brain injury. A small number of people advised they had self-funded additional support, or availed of counselling services provided by the voluntary or charitable organisations.

### **Information**

Participants in all focus groups had different opinions about the information provided in relation to brain injury. Many people did receive information; however, the amount of information and when it was provided varied greatly.

Some people reported having received a lot of information. Although they felt this was helpful, many felt that it was too much information, and looking back, felt that it was provided at the wrong time. Some advised that they had only received basic information and this was not adequate. Many people advised that they did not receive any information and had to find it themselves, either from the internet, or from voluntary or charitable organisations.

Many people stated that they were not aware of the services available to them, or whom they could contact if they needed help.

### **Voluntary and Charitable Organisations**

All focus group participants spoke very highly of voluntary and charitable organisations. They praised the roles undertaken by these organisations in providing support for people living with brain injury. Everyone stated that support groups provided by voluntary organisations were extremely important, enabling them to meet other people experiencing the same problems. However, many people considered that there should be more communication and better linkage between the trusts and the voluntary sector.

### **Suggestions for improvement**

As part of the focus group discussions, participants were asked for their opinions about how they felt brain injury services could be improved. They advised the following:

- More information about brain injury should be made available.

- Improved communication between healthcare staff and patients.
- Provide information at different stages of the brain injury journey.
- Provide a longer term service for people with brain injury.
- Increase the number of staff on wards that look after people with a brain injury.
- More help for families and carers.
- Increase in rehabilitation provided.
- Include a social aspect to the rehabilitation.
- More training for GPs to recognise brain injury.
- An increased awareness of brain injury and its consequences.
- More involvement from service users in relation to asking opinions about improvements to services.
- Development of an accommodation plan.

### **Views of carers and family members of children with a brain injury**

The number of carers and family members with a child with a brain injury, who engaged in the focus groups, was considerably lower. They reported a range of different experiences. The majority of carers and family members reported having negative experiences, mainly because their children were never diagnosed as having a brain injury. The people who recalled more positive experiences, all advised that their child was diagnosed with a brain injury.

Participants reported that during their child's stay in hospital, they felt that medical staff were unable to provide them with information about their child's condition. They recalled staff telling them on different occasions, "to wait and see what happens". Several people advised that they had not been provided with any information upon discharge, and that they would be contacted by the community nurse. However, there was no follow up by community teams when they returned home.

Those people, whose child had been admitted, stated that the ward environment was often noisy and a lot was happening. They said that their children did not receive any rehabilitation while on the ward, and stated that staff sometimes did not recognise the needs of their child.

There were mixed views about the level of care provided to children by community staff. Some people reported that no care was received, while others stated that social work, speech and language, occupational therapy and physiotherapy all had an input into their child's care. However, people stated there was no joint approach to the care being provided.

The overall feedback from carers and family members of children with a brain injury was that in contrast to adults, there are little or no services provided for children. Parents felt that their children had not received the right care and support, and there was little positive feedback in relation to the trusts and what they provide for children with a brain injury. Parents felt that there are many other parents who feel the same, but not all are strong enough to speak up regarding their children's treatment.

## **2.2 Organisation of Brain Injury Services**

There are distinct differences between brain injury services provided by trusts for adults when compared with children's services. Adult brain injury services are predominantly community based, and there is no specific brain injury service in the acute hospital setting. Community brain injury teams have varying amount of input into the acute hospital setting. There is no separate brain injury service for children in either the community or in the acute hospital setting. Children with brain injury are cared for within the relevant specialty of children's services, for example neurology, which focuses on the child and not the condition. This model of care is consistent with most brain injury services in the United Kingdom.

### **Adults with a Brain Injury**

Adults presenting at the Emergency Department with a possible brain injury are assessed and treated according to the severity of the injury. Patients with a mild brain injury with no ongoing symptoms are usually discharged. The admission of patients with a moderate to severe brain injury, and their subsequent care, is provided on a relevant medical or surgical ward, or in the Belfast Trust's neurosciences wards, unless they have other conditions. There is no specific inpatient brain injury service within the acute hospital setting. More severe cases are cared for within the intensive care unit, or transferred to the Belfast Trust.

Post-acute inpatient rehabilitation is provided within four units:

- Regional Acquired Brain Injury Unit – Belfast Trust
- Innisfree Ward – Belfast Trust
- Thompson House Hospital – South Eastern Health and Social Care Trust (South Eastern Trust)
- Spruce House – Western Health and Social Care Trust (Western Trust).

Each trust has a community brain injury team for adults, which provides rehabilitation, support and advice to people living with brain injury and their carers.

Some specialist services are commissioned from outside Northern Ireland. These out of area placements are commissioned for adults with extremely challenging behaviour or with complex care needs, which cannot be met within Northern Ireland.

### **Children with a Brain Injury**

The care of children with a brain injury is not focused on the condition, but rather on the child, within a relevant specialty, such as neurology. This model of care is consistent with children's services provided for most conditions. Children presenting at an ED with a brain injury are assessed and treated according to the severity of the injury. Children with a mild brain injury are

usually discharged, or admitted to a children's ward for observation. Children with a moderate to severe brain injury are usually transferred to Paul Ward in the Royal Belfast Hospital for Sick Children (RBHSC), within the Belfast Trust.

There are no dedicated children's inpatient rehabilitation facilities throughout the trusts, and the only services for children's inpatient rehabilitation are within the Belfast Trust, though these are shared with other specialities and are not dedicated to brain injury. In the community, children are cared for by each trust's children's community team.

In common with adult services, some specialist services for children are commissioned from outside Northern Ireland. These out of area placements are commissioned for children with extremely challenging behaviour or with complex needs.

### **Strategic direction**

All trusts advised that there is a lack of strategic direction in relation to brain injury services. They highlighted that there is no mechanism to plan in partnership with other trusts. Some trusts indicated that their strategic direction was being driven from within their individual trust, and was based on the brain injury standards. The review team considered this to be an area for concern, particularly, as the 2008 review of brain injury services also identified an insufficient focus on strategic planning and management.

Following the 2008 review of brain injury services, a Regional Acquired Brain Injury Implementation Group (RABIIG) was established, under the chairmanship of the HSC Board. With associated funding, RABIIG was responsible for making improvements to brain injury services through the implementation of the recommendations from the review. RABIIG addressed many of the original recommendations in order to support the full implementation of the brain injury standards.

The review team noted that some of the original review recommendations had not been fully implemented. The review team considered that of the 23 recommendations from the 2008 review of brain injury services: 10 recommendations were fully implemented; 3 recommendations were partially implemented; and 10 recommendations were still to be implemented.

Membership of RABIIG included representatives from the HSC Board, Public Health Agency (PHA), trusts, statutory bodies, voluntary organisations, service users, carers and family members. The review team acknowledged the good work achieved by RABIIG and the products it delivered, in particular the brain injury standards and care pathways. The review team considered that RABIIG provided appropriate strategic leadership and drive to effect necessary changes and service improvements within brain injury services.

In 2012, the decision was taken that RABIIG could not continue indefinitely, and that it would be stood down in February 2013. The responsibility for brain injury services, and taking forward the outstanding actions from the brain

injury action plan, formerly the responsibility of RABIIG, was to be incorporated within the Physical and Sensory Disability (PSD) Strategy and Action Plan 2012-15. The rationale for this decision was that the many of the original brain injury actions had been completed, and that RABIIG representatives would input into the delivery of the PSD strategy and action plan 2012-15.

A Disability Strategy Implementation Group was established to direct, coordinate and manage the implementation of the PSD action plan. This group was to continue in existence over the three year period 2011-12 to 2014-15. It was not clear to the review team what the timescales were for the implementation group to be stood down, and there was no indication as to who would provide oversight of brain injury services in the future.

Over the course of implementation of the PSD action plan, it was accepted that there may be a requirement to develop additional or more detailed actions. The review team was advised that the outstanding actions from the brain injury action plan were embedded in the PSD action plan. The HSC Board also prioritised the outstanding actions, and informed the Department of Health, Social Services and Public Safety (DHSSPS) of their status prior to incorporating them into the PSD action plan.

During the review, there was limited reference by trust staff, both operational and managerial, to the PSD strategy or action plan. No one considered that the PSD strategy was an appropriate driver for providing strategic direction for brain injury services. Trusts also advised that it was not possible to add specific brain injury issues to the PSD action plan. Upon review of the PSD action plan, the review team was unable to identify any of the specific outstanding brain injury actions. However, some areas currently being taken forward through the PSD action plan may be beneficial to patients, carers and family members using brain injury services, as they are generic to all disabilities.

With the current arrangements for brain injury being incorporated within the remit of the PSD strategy, the review team was of the opinion that brain injury services had lost their strategic focus, which prevented services moving forward in a coordinated way. The team also considered that the outstanding actions from the brain injury action plan would not be appropriately addressed by the PSD action plan.

As there is no specific brain injury service for children, the review team was unable to clearly identify where responsibility lay for provision of strategic direction for this area of care. The HSC Board considered the Children's Services Improvement Board and the Children and Young Peoples Strategic Partnership contributed towards the strategic planning for services. Although children's services are heavily prescribed by legislation and are subject to numerous government policy documents, service frameworks, action plans, reports and guidance, they are generic and not specific to brain injury. However, the review team acknowledged the need for the provision of such legislation and guidance in relation to children's services.

Children's brain injury had been included within RABIIG and benefitted from work undertaken by the regional group, in particular, development of a specific care pathway for children and young people. However, with the dissolution of RABIIG, there is no mechanism for a regional coordinated approach for children's brain injury services. The review team considers that representatives from children's brain injury services should be included in any future regional managed network.

Within children's services, pathways, protocols, and guidance for the transfer and transition of children between services have been developed; however, these are generic documents and not specific to brain injury. In some cases, the generic documents were not always appropriate when dealing with a child with a brain injury. Although there is a specific regionally developed care pathway for children and young people, it was unclear to the review team as to how extensively this was being used, if at all.

In all meetings, staff spoke about the need to develop a regional clinical network for brain injury. The benefits of RABIIG were shared with the review team, and staff advised that this source of support and development was now missing. Both operational and managerial staff considered that a clinical network opened up opportunities for shared learning and development and provided a forum for identifying gaps in service, discussing complexities, and developing service improvements.

The review team recommends that the HSC organisations meet to discuss and agree the establishment of an appropriate regional structure for brain injury, which will set and drive the strategic direction for brain injury services. This network should incorporate the HSC Board, trusts, representatives from the voluntary and charitable organisations, and service users. It should also have responsibility for taking forward the implementation of any outstanding actions from the brain injury action plan and update work streams based on emerging evidence.

#### **Recommendation 1**

**The HSC Board and trusts should meet to discuss establishment of an appropriate regional structure to facilitate the continued development and improvement of brain injury services.**

### **2.3 Standard 1: Organisation of Care for People with Acquired Brain Injury**

#### **Responsibility for brain injury services**

All trusts, with the exception of the Northern Health and Social Care Trust (Northern Trust), had an identified senior manager with responsibility for the planning and review of adult brain injury services. The senior manager in the Northern Trust had retired a few weeks prior to the review and a replacement

had not yet been appointed. The HSC Board also had an identified senior manager with responsibility for adult brain injury services. Each trust had also appointed a senior clinician with responsibility for the coordination of adult brain injury services.

With regard to children's services, the Western and South Eastern trusts had a specific senior manager with responsibility for planning and review of children's brain injury services. The other trusts advised that they had senior managers with this responsibility, but these were not specifically named to the review team, and it was only a part of their role. Trusts had formal meetings with the HSC Board to discuss children's services, where emerging service pressures were discussed. These discussions included all aspects of children's services and were not specific to brain injury services.

Only the Belfast Trust reported having a senior clinician with responsibility for the coordination of children's brain injury services. This was consistent with the Belfast Trust providing the regional service.

While there is no specific children's service for brain injury, the review team spoke to a number of key members of staff in each trust that have taken a particular interest in children's brain injury. The review team considered that it was their drive and enthusiasm that was making a positive contribution to the level of care being provided.

### **Integrated working**

It was clear to the review team that there was only limited collaboration between trusts in relation to service improvement. The review team found that trusts were taking forward different aspects of the brain injury standards, based on issues that were a priority for them. It was also the case that some trusts were working on similar service improvement initiatives, essentially duplicating work. The review team considered that a joined up approach would be more efficient and lead to a greater exchange of ideas.

The review team explored the arrangements for integrated working within and between trusts. Care pathways, which had been developed by RABIIG, were in place for neurorehabilitation, adult community care and children and young people. These were available in all trusts.

In addition to the care pathways, each trust had a range of protocols, guidance and referral documents available for internal and cross trust management of patients. Although the various documents were specific to brain injury, there was limited consistency between trusts in relation to their type, number or content. The review team considered that closer coordination between trusts may have facilitated a standard suite of documents.

The current organisation of brain injury services across Northern Ireland, along with the development of standards, has influenced the interface arrangements within and between trusts. A weakness of the brain injury standards and associated action plan is their focus on the care of medically

stable patients in the post-acute phase of treatment, care and support. This limits their impact and subsequent use within the acute hospital setting, which was reflected during the review.

Information obtained during the review indicated that there were closer links between the acute hospital setting and the regional rehabilitation service, than between the acute hospital setting and the CBITs. The links between the acute hospital settings and regional rehabilitation services were strongest within the Belfast Trust. This was a result of the Belfast Trust having responsibility for the provision of the regional rehabilitation service, and the fact that many of the medical staff working in RABIU also worked on neurosciences wards in the Royal Victoria Hospital. Strong links were reported between Thompson House Hospital and RABIU, as some consultants work across both sites. Robust links between Spruce House and Altnagelvin Hospital were observed due to their co-location on the same site. Strong links were reported between the post-acute rehabilitation units and the CBITs.

While there are links between the acute hospital services and CBITs, these were more often driven and maintained by staff from the CBITs. In the Belfast Trust, a head injury liaison nurse regularly interfaced with staff within the ED to assist with patient assessments and provide advice on head injury. They were the key link for informing RABIU and the CBITs about patients within the acute hospital setting. An early intervention nurse in the Northern Trust, and an early intervention social worker in the Southern Health and Social Care Trust (Southern Trust), undertook similar roles for identifying and referring potential brain injury patients. There was no such role within the South Eastern or Western Trusts.

The 2008 review of brain injury services recommended that 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. The review team considered this recommendation is still valid, and consideration should be given to the establishment of such a role in the South Eastern and Western trusts.

## **Recommendation 2**

**Where not already established, trusts should consider development of a role linked to specialist brain injury services, to identify and facilitate the pathway for people with a brain injury in acute and general inpatient wards.**

It was also reported that the turnover of staff in the acute hospital setting was a further contributing factor that impacted on the interfaces between services. The review team was informed that many new staff were not always aware of the arrangements for referral of patients to the CBITs. Cases were reported to the review team of appropriate referrals not being made from the acute hospital setting to CBITs, particularly for those patients that did not require inpatient rehabilitation. For some cross trust referrals, cases were also

reported of patients being referred from the acute hospital setting to generic community teams, rather than to the CBITs.

Staff also advised that they had to frequently re-educate staff about the arrangements for informing patients of the role of the voluntary and charitable organisations. The review team recommends that trusts promote the awareness of CBITs and the use of appropriate referral pathways into this service. Trust may want to consider utilising the nurse linked with brain injury specialist services to facilitate this.

A gap was highlighted in relation to the integrated working between brain injury services and mental health teams. Staff advised that in some cases referrals were not accepted, and mental health services appeared to be reluctant to accept brain injury patients. If referrals were accepted, there were long waiting times reported.

### **Recommendation 3**

**Trusts should review their liaison arrangements between the brain injury services and mental health services, to ensure there is integrated working between services.**

Despite care pathways and protocols being in place, successful interface working often was achieved as a result of personal relationships developed between teams and departments, rather than effective care pathway management. There were many key people throughout the brain injury services that were the drivers for change and service improvement.

Within children's services, a key regional service that enhances the interface links between trusts is the children's acquired brain injury consultation service (Children's ABCS). In 2011, the HSC Board commissioned the Children's ABCS in response to the 2008 review of brain injury services. The service is in recognition of the need to augment core services across health, education and voluntary sectors in better understanding and meeting the needs of children, young people and families following a brain injury. This service provides support for community teams, including advice and training on dealing with a brain injury. Staff advised that the service was not set up to see children, and would not have the capacity to see them. All trusts commented on the benefits of this service and stated it was very responsive. The review team was concerned that it was not sufficiently resourced to meet current demand.

### **Recommendation 4**

**The capacity of the children's acquired brain injury consultation services should be reviewed to determine if it is sufficiently resourced to meet increasing demand for their services, and appropriate action taken based on the findings.**

The review team considered that links between the acute hospital setting and regional services were seen to be much more coordinated within children's services. Royal Belfast Hospital for Sick children staff had established reciprocal links with their peers in local and regional hospitals, which provided the framework for referrals. Although referral protocols were available, the majority of referrals were considered on a case by case basis. Capacity on the ward acted as the only restriction for accepting a referral.

Despite the care pathway for children and young people with a brain injury, staff reported there was no formal referral pathway for children being discharged from the Belfast Trust back to other trust's community teams. Staff also advised of not knowing who to contact within children's community teams. The review team considers that all trusts should develop and make available, appropriate information regarding team structures, including contact details, which can facilitate discharge back to trusts. This should be shared between all trusts.

The review team noted that many children, who presented at the ED with a head injury and were not admitted, were unlikely to be referred to community services for follow up. It must be noted that many of these children would make a full recovery and would not require the follow up of community teams; however, the importance of appropriate referral should not be underestimated as a number of children may return at a much later date exhibiting behavioural problems.

#### **Recommendation 5**

**Trusts should develop appropriate information about community team structures for both children and adult services. This information should be shared within and between trusts, to facilitate discharge back to the community setting.**

#### **Training and staff competencies**

Staff competencies in relation to brain injury were inconsistent across different trust settings. The review team considered that a contributing factor to this may be the focus of the brain injury standards being more on the post-acute phase, rather than on the acute hospital setting. This has led to staff training on dealing with patients with a brain injury within the acute hospital setting not being as well developed as staff training within the CBITs.

There was no mandatory training for staff on dealing with patients with a brain injury within the acute hospital setting. Most staff within the ED would only have received training on dealing with brain injury during their general training. Further knowledge was then only obtained through experience of treating patients with a brain injury, or interaction with CBIT. However, it was reported that in the Belfast Trust, staff within the ED and the Emergency Surgical Unit received training on head injury management and neurological observations. In the Western Trust, a specialist brain injury nurse is providing a range of awareness training across the acute sector.

There were no issues identified with the competencies of staff within neurosciences wards, as they had undertaken appropriate brain injury training related to this specialty. Staff within RABIU were appropriately trained. However, patients whose brain injury was not the primary condition were being treated on non- neurosciences ward by staff that lacked the specialist knowledge of dealing with a brain injury.

Within the community setting, provision of brain injury training was limited to staff within the CBITs. Appropriate training was identified during annual appraisals, against the knowledge and skills framework. When additional training specific to brain injury is identified as a need, it is provided where possible.

There was varied amounts of evidence between trusts in relation to the level of specific brain injury training that generic community teams had received. Information provided by people living with brain injury and their carers during focus groups, indicated that the generic community teams lacked knowledge in relation to brain injury, and were unable to appropriately address their needs. The Northern Trust advised that social workers in the generic community teams received training from the CBIT on brain injury. The Southern Trust advised that staff within the generic community teams received regular awareness training in relation to brain injury.

The review team noted that core competencies specific to children with a brain injury had not been developed. However, the team considered that staff within children's services, working with children with a brain injury, had the required skills and competencies to undertake their roles effectively.

RABIIG published a training framework for staff working in services for children post brain injury. The framework identifies different levels of training and training providers. The Belfast Trust was using this framework to inform its approach to training. Staff from the Children's ABCS were providing training to staff from all trusts, based on this framework.

The Child Brain Injury Trust also provided training on children's brain injury to staff from all trusts.

#### **Recommendation 6**

**Appropriate training on dealing with patients with a brain injury should be provided for generic community teams and staff working on non-specialist brain injury wards.**

#### **Links with voluntary and charitable organisations**

All trusts had good links with voluntary and charitable organisations and had worked with most of them as part of RABIIG. Voluntary and charitable organisations were commissioned to provide services by each trust, although the services varied depending upon the particular needs of the trust. Services

provided include vocational and training support, rehabilitation programmes, services relating to social inclusion and day opportunities, building capacity in local communities, and supported living. With the exception of a few regional services, there did not appear to be any strategic approach to the provision of services on a regional basis. Trusts reported good working relationships with the voluntary and charitable organisations, and also informed patients about other organisations they did not explicitly commission services from.

Trusts had contractual and governance arrangements in place with the organisations they commissioned a service from. These included regular monitoring and recording of service usage and monthly meetings with trust staff. The HSC Board also commissioned services from Headway and Reconnect, to provide counselling and vocational training.

The review team was made aware that a growing number of voluntary and charitable organisations are now available to assist people living with a brain injury. Some of these organisations were not currently being commissioned to provide any services. This growth has led to more competition between providers for trust referrals and contracts. Trusts advised that due to the increasing numbers of providers, leading to an increased level of competition, it is important that robust commissioning and contractual arrangements should be in place.

There were fewer voluntary and charitable organisations that focused specifically on children with a brain injury. A key organisation was the Child Brain Injury Trust. The Cedar Foundation provided services for children; however, this was for all children with a disability and not specific to children with a brain injury. Brain Injury Matters also provided some services for younger people aged from 16 to 20 years. The HSC Board commissions services from the Child Brain Injury Trust to provide support for children with a brain injury, their carers and families.

With the exception of the Belfast Trust, all trusts had developed strong links with and regularly utilised the services of the Child Brain Injury Trust, to provide support for families. Even though the HSC Board commissions the service, the Belfast Trust made limited use of the Child Brain Injury Trust, and their referrals to this organisation were limited. The review team was therefore concerned that provision of support for families was a potential gap in the trust service, particularly as the regional children's inpatient rehabilitation was within the Belfast Trust. The review team considered that as the Belfast Trust was not fully utilising the commissioned service, this should be discussed with commissioners in order to ensure that families were receiving appropriate support.

#### **Recommendation 7**

**The Belfast Trust, in conjunction with the HSC Board should evaluate its relationships with voluntary and charitable organisations providing services to children with a brain injury, their families and carers, to ensure a coordinated approach to the provision of services.**

The review team saw little evidence of a regional approach to commissioning of services from voluntary and charitable organisations. The HSC Board informed the review team that there were three levels of commissioning within brain injury services involving these organisations. Services were commissioned by DHSSSPS, the HSC Board and also by trusts, with no evident coordination between these three bodies in relation to the types of service being commissioned. The HSC Board acknowledged the difficulties associated with these arrangements.

The HSC Board has two regional contracts in place, with the Child Brain Injury Trust and the Cedar Foundation, to provide services for children with a brain injury and their families. There were appropriate contractual and governance arrangements in place. These included regular monitoring and recording of service usage, and regular meetings with HSC Board staff.

### **Links with statutory bodies**

Within adult services, there were some instances of links between trusts and other statutory bodies. Some trusts had direct involvement with the Northern Ireland Housing Executive for developing supported accommodation arrangements for some patients. The Western Trust had established contractual arrangements with the Cedar Foundation and Leonard Cheshire to provide services which linked with education and training agencies.

Within children's services, there were definite links between the trusts and other statutory bodies. Many of these links are prescribed by legislation, and arrangements were established across all children's services, and not specifically for children with a brain injury. All trusts were involved in collaborative working across the range of agencies engaged with children. Trusts had direct involvement with schools and the education authorities, and juvenile justice.

### **Data Collection**

The brain injury standards stipulate that trusts should collect and collate data on activity at all points in the patient pathway. This is to demonstrate that: patients' needs are being met; the care provided has a positive impact on the patient and their family; and the data is being used to plan and coordinate future service provision. The review team found that all trusts were collecting activity data from various aspects of the patient pathway. However, there was no consistency between trusts in relation to the areas where the activity was being monitored, or the type of data being collected. Where data was being collected it was more in line with the individual trust's governance reporting arrangements, rather than developing a standardised data set to inform brain injury services.

During the review, it was identified that no agreement or guidance was developed in relation to the type of data to be collected. No standard audit tools have been developed. With the dissolution of RABIIG and an absence

of any appropriate regional structure, there was no mechanism to take this forward or agree on any regional data sets. The United Kingdom Rehabilitation Outcomes Collaborative (UKROC)<sup>7</sup> has established data sets for collating case episodes for inpatient rehabilitation, which may be a useful reference for taking this forward.

Trusts provided evidence of some service improvement initiatives developed as a result of data collection, and subsequent reporting to the HSC Board. However, at a regional level, there was little evidence of performance management information being used to inform service development, or plan effectively the future provision within brain injury services.

The review team considers that performance against quality indicators contained in the brain injury standards, would be enhanced by developing appropriately defined regional data sets. As well as setting out a requirement to collect data on activity at all points in the patient pathway, the standards also contained a requirement to carry out audit to demonstrate activity and impact.

The review team saw very little evidence of any audit taking place. The review team also considered that in the absence of data collection and audit, it would be very difficult for commissioners to assess the quality of the service they were receiving.

Within children's services, trusts collected activity data from various aspects of the patient pathway. However, the data collected was more consistent with the requirement to inform the trusts' delegated statutory functions report, than that which might lead to service improvements within children's brain injury services.

### **Recommendation 8**

**The HSC Board in conjunction with trusts should develop appropriately defined data sets and audit tools to support a system of audit against the quality indicators contained in the brain injury standards.**

### **Involvement of service users and carers**

The involvement of patients, carers, and family members should be an integral aspect for the development of brain injury services. This level of involvement falls within the definition of Personal and Public Involvement (PPI).

All trusts provided evidence of how patients, carers, and family members had been involved in specific pieces of work associated with brain injury. This ranged from being involved in satisfaction surveys about the services,

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<sup>7</sup> United Kingdom Rehabilitation Outcomes Collaborative (UKROC) - <http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/research/studies/ukroc/index.aspx>

consultation about patient information, focus groups to obtain opinions and feedback on issues related to brain injury.

In the South Eastern Trust, patients, carers and family members were involved in the planning and development of a new neurodisability and acquired brain injury supported living scheme. The trust had also involved patients, carers, and family members in stakeholder groups, as part of a project to develop a self-management book<sup>8</sup> for acquired brain injury. The review team considered this as an area of good practice.

While patients, carers, and family members have been involved in specific pieces of work, they have very limited involvement in the overall planning and development of brain injury services. Progress has been made to involve people in the development of services; however, this does not meet the legislative requirement of PPI.

In March 2015, the PHA launched the standards for Personal and Public Involvement – Setting the Standards<sup>9</sup>, which were developed to set out what is expected of HSC organisations and staff. The review team considers that that the HSC Board and trusts should use the Person and Public Involvement standards as the basis on which to involve patients, carers, and family members in the development of brain injury services

### **Recommendation 9**

**The HSC Board and trusts should use the Personal and Public Involvement Standards as the basis on which to involve patients, carers and family members in the development of brain injury services.**

## **2.4 Standard 2: Early Acute Management for People with Acquired Brain Injury**

### **Adults with a Brain Injury**

Most adults presenting at the ED with a head injury recover without specific or specialist intervention. The earlier a patient can be assessed and treated, the greater the potential to identify and minimise complications. However, for moderate to severe cases of brain injury, early acute intervention and management, though still extremely important, may only limit the effects of complications.

The differing levels of input and engagement from some staff within the acute hospital setting, reflected the lack of influence the brain injury standards had

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<sup>8</sup> This project is run in partnership with the Bridges Self-management, St George's University of London and Kingston University. - <http://www.bridges-stroke.org.uk/>

<sup>9</sup> Personal and Public Involvement – Setting the Standards 2015 – Public Health Agency - <http://www.publichealth.hscni.net/directorate-nursing-and-allied-health-professions/allied-health-professions-and-personal-and-publi-5>

on clinical practice. In particular, the standards stipulated several policies and protocols that should be available in the acute hospital setting. These included protocols for the assessment of post-traumatic amnesia, ongoing care of patients, and assessment for transfer to neurosurgery; and a policy for the management of mild traumatic brain injury. These documents were not presented as evidence to the review team. The review team identified that, within the acute hospital setting, more emphasis was placed on the National Institute for Health and Care Excellence (NICE) guidance<sup>10</sup> on head injury, rather than the brain injury standards.

With the exception of the Belfast Trust, all trusts provided a copy of their operational policy for managing patients with a brain injury. Copies of other policies, protocols and local guidance developed to help staff care for patients with a brain injury were also submitted. These documents were produced by the CBITs and although they covered the full care pathway, they were predominantly focused on post-acute care. The acute hospital setting was referenced in these documents, and information was available for them to use; however, the review team could not determine whether they were being used in most trusts. Documents submitted by the South Eastern Trust were specific to the ED and acute hospital setting. None of the other trusts submitted documents that specifically related to the ED.

Adults presenting at the ED with a head injury are assessed and treated according to the severity of the injury. Trusts advised this was carried out in line with the current NICE guidance on head injury and their own local policies.

Patients assessed with having a mild brain injury and no ongoing symptoms were usually discharged. Upon discharge, patients were provided with advice on what to do if their symptoms do not improve, or get worse. All trusts provided a copy of the information leaflet given to patients discharged from the ED. Although this information was provided, no trust had a written protocol on when and to which patients such advice should be given.

None of the trusts had a written protocol for the assessment of post-traumatic amnesia assessment in patients. Post-traumatic amnesia is the early stage in recovery from a brain injury when the patient is no longer unconscious but is confused, disorientated and often exhibits behavioural disturbance. The review team considered this was an essential requirement as part of the assessment and treatment process. The review team considers that an assessment tool for post-traumatic amnesia should be developed and implemented in all trusts. This should include children, as no assessment tool was available for children with a brain injury.

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<sup>10</sup> NICE clinical guidelines 176 - Head injury: Triage, assessment, investigation and early management of head injury in children, young people and adults - <https://www.nice.org.uk/guidance/cg176>

## **Recommendation 10**

**Trusts should develop and implement a written protocol for the assessment of post-traumatic amnesia in both children and adults, for use within Emergency Departments.**

On assessment of evidence, the review team identified a cohort of patients that they considered had the highest possibility of missing out on appropriate care. These were patients with a mild brain injury who had been discharged, but may go on to develop further problems.

The Southern Trust, using information obtained from focus groups, had subsequently developed a leaflet for use within the ED to provide information for this cohort of patients. Although they might have been given advice or an information leaflet upon discharge, no trust had a protocol for the ongoing care of these particular patients, post discharge. As a minimum, these patients should have been referred to a CBIT for follow up.

In the Belfast, Northern and Southern trusts, early intervention staff usually identified these patients, and made the referrals to the CBITs. The early intervention staff worked in partnership with staff in the acute hospital setting to identify people with potential brain injury. They provided advice on the management of these patients. In the South Eastern and Western trusts, this role was not established, and the responsibility for referrals to the CBITs lay with the ED staff, and referrals were sometimes missed.

All trusts had protocols in place for the referral of patients to a CBIT. However, some referrals were being missed, particularly for patients with a mild brain injury and especially in those trusts with no early intervention staff. As this responsibility lay with the ED staff, the pressures within the ED may have contributed to this.

Patients with a moderate to severe brain injury are usually admitted to, and have their subsequent care, provided in a relevant medical or surgical neurosciences ward. However, on occasion, patients were admitted to other wards. More severe cases are also cared for within an intensive care unit, or transferred to the Belfast Trust from other trusts.

Although some trusts referenced the admission of patients to neurosciences wards in their operational policy, no evidence of formal protocols for the assessment and transfer to neurosurgery was provided to the review team. Trusts informed the review team, that within hospitals, this transfer was routine and staff were aware of their roles and responsibilities. For transfers from another hospital to the Belfast Trust, this was generally initiated and discussed between consultants prior to any transfer. These transfers then followed general transfer protocols.

Patients with multiple conditions, whose brain injury was not their primary condition, would usually end up being admitted to a general medical or surgical ward. They would be treated for their primary condition and generally

did not receive the appropriate level of care for their brain injury. However, had they been on a neurosciences ward, they may not have received appropriate care for their primary condition. The review team acknowledged the difficulties involved with treating patients with multiple conditions, but highlighted that patients should be transferred to neurosciences or specialist neuro-rehabilitation facilities as soon as they are medically stable.

Patients with a brain injury as their primary condition were generally admitted to neurosciences wards. The length of time that patients remained in acute wards was dependent on their condition and the availability of the post-acute rehabilitation.

For many patients, remaining on acute wards was problematic in relation to their rehabilitation. Although therapeutic interventions were available on these wards, care was provided by general therapists not specifically trained in brain injury. In the Belfast Trust, physiotherapy staff working on acute wards could liaise with the specialist neuro-rehabilitation physiotherapists for specialist advice and management if required. The level and frequency of therapy provided on acute wards was much less intense than staff thought was clinically required. There was no specialist psychology service available to brain injury patients on acute wards. In the Northern Trust, the CBIT has offered support on the ward to assist with the management of patients with challenging behaviour.

#### **Recommendation 11**

**Trusts should develop protocols for the management of brain injury patients accommodated in general wards. The protocols should include liaison arrangements with specialist multidisciplinary teams and brain injury services for advice and management of these patients.**

While on the wards, patients were assessed and treated by multidisciplinary teams. However, information provided during the focus groups indicated that discussions were more focused on discharge or onward referral, rather than on identifying and setting rehabilitation goals. With no specialist multidisciplinary assessments being undertaken, the review team found it difficult to understand how some patients were being appropriately assessed for discharge.

There were no discharge protocols specifically for patients with a brain injury, and all discharges followed general discharge protocols.

#### **Recommendation 12**

**Trusts should develop protocols for the management of brain injury patients accommodated in neurosciences wards. The protocols should include rehabilitation planning, discharge and liaison arrangements with community brain injury teams.**

## Children with a Brain Injury

Most children presenting at an ED with a head injury will not require specific or specialist intervention. However, as children's brains are continuously developing, for some children the full effects of a head injury may not be apparent until several weeks or even years in the future. It is possible that developmental and behavioural issues in children may be linked with a past head injury. Staff advised that more children are coming into the system that are long term post injury, and presenting with behavioural difficulties.

With the number of different policies, service frameworks, action plans, and guidance governing the care of children, the review team was concerned about the level of recognition that was given to the brain injury standards and the associated care pathway for children and young people. Despite being outlined in Standard 2, there were no policies or protocols specific to brain injury, associated with the early management of children.

Children presenting at an ED with a head injury are assessed and treated according to the severity of the injury. Trusts advised this was carried out in line with the current NICE guidance on head injury and their own local policies.

Children assessed with a mild brain injury with no ongoing symptoms were usually discharged. Upon discharge, the parents were provided with advice on what to do if their symptoms do not improve or get worse. Only the Belfast Trust provided a copy of an information leaflet given to patients discharged from the ED. No written protocol on when to provide such advice was available in any trust.

Trusts advised that following presentation at an ED, a referral is made to a health visitor or social worker for possible follow up. This was a generic referral process and was not specific to brain injury. Some staff advised that they considered the care pathway for children was not working for those with a mild brain injury, as they often got missed. The review team was unable to determine how successful this process was and whether all children with a head injury were being followed up. The review team considered that follow up of children with a mild brain injury was an issue that trusts should review as to the quality of their processes.

### **Recommendation 13**

**Trusts should review their processes for the follow up of children with a mild brain injury.**

The admission of children with a brain injury depended upon the severity of the injury. Children with mild to moderate head injuries who did not require neurosurgery or paediatric intensive care were admitted to paediatric wards within the district general hospitals. Children with moderate to severe head injuries, which required either neurosurgery or paediatric intensive care, were referred to Paul Ward in the RBHSC, in the Belfast Trust. At the time of the

review, there was no formal protocol for the transfer of children to RBHSC.

Clinicians from other trusts could request an assessment of a child, with a view to transfer to RBHSC. The child would be transferred and assessed in the ED, prior to admission. If the child is seriously unwell, and it is clinically indicated, the child would be intubated at the other site and transferred to PICU. Neurosurgery will accept a direct transfer from other hospitals if definitive neurosurgical input is required.

The Paul Ward in the RBHSC is no longer a specialist neurology ward. The ward accommodates a variety of specialities, such as neurology, neurosurgery, dermatology and burns. This has resulted in beds no longer being dedicated for brain injury patients, with some children with a brain injury being admitted to other wards. Having to care for so many different conditions is also diluting the specialist brain injury skills of the staff. With no dedicated paediatric rehabilitation unit, children with brain injury were more likely to be discharged, when they were medically stable, back to local trusts. However, the district general hospitals do not have the specialist therapy and nursing staff, or experience, for appropriate post-acute rehabilitation.

Staff informed the review team that the current arrangements within Paul Ward did not make it a suitable environment for neurology patients.

#### **Recommendation 14**

**The Belfast Trust should prioritise the provision of (i) a suitable ward environment for neurology patients, and (ii) acute neurological rehabilitation facilities within the new children's hospital.**

### **2.5 Standard 3 Post-Acute Inpatient Rehabilitation**

Brain injuries can affect many aspects of a person's life. Therefore, it is important to provide appropriate rehabilitation to help them reach and maintain optimal functioning levels, in areas such as cognitive, sensory, physical and social behaviour. Inpatient rehabilitation is provided within four units across Northern Ireland.

- The Regional Acquired Brain Injury Unit is a purpose built, specialist rehabilitation unit situated within the grounds of Musgrave Park Hospital, in the Belfast Trust. RABIU functions as a tertiary referral centre for highly complex cases and provides a secondary referral role, for patients who do not have access to inpatient rehabilitation within their own trust area.
- Innisfree Ward is a neurobehavioral rehabilitation unit situated within the grounds of Knockbracken Healthcare Park, in the Belfast Trust. It is a specialist facility for males, providing rehabilitation treatment, care and support to people who present with significant neurobehavioral problems as a consequence of brain injury.

- Thompson House Hospital, in the South Eastern Trust, is a regional specialist unit that provides assessment and rehabilitation (slow track and fast track), therapeutic short break care and neuro-palliative services for people with complex neurodisability.
- Spruce House is a specialist facility situated at Altnagelvin Hospital, in the Western Trust. The unit provides assessment, rehabilitation, short break care and transitional care for people with acquired brain injury.

No issues were raised in relation to the general health and safety of the rehabilitation units. The review team did not visit Innisfree, so could not comment on this unit. There are no post-acute inpatient rehabilitation facilities in the Northern or Southern trusts.

There are no dedicated facilities for children's inpatient rehabilitation throughout the trusts with the exception of the Belfast Trust which provides the only inpatient rehabilitation service. It is only in exceptional circumstances that RABIU would accept the admission of a child over the age of 14 years. Post-acute rehabilitation is carried out in the community.

There is no dedicated outpatient rehabilitation service for children with a brain injury. The clinical psychology department within the RBHSC provides a regional outpatient services to children under the care of neurosciences services. However, the staffing compliment is small and covers many neurological conditions, as well as brain injury.

## **Referral Systems**

Trusts submitted their procedures for referral to post-acute inpatient rehabilitation units, and written documentation about the rehabilitation facilities, including their access and exclusion criteria. Upon review of the information, the review team considered that information and referral procedures were more clearly outlined within the neurorehabilitation care pathway which provides better and more detailed information regarding rehabilitation units. However, this care pathway was not referenced by staff during the meetings with the review team.

The review team considered that the information currently being used, relating to post-acute inpatient rehabilitation, needed to be reviewed and updated. The information should more clearly reflect what is outlined in the brain injury standards and the neurorehabilitation care pathway.

The review team also considered the admission policy currently being used by RABIU to be very basic. It did not reflect the standard of documentation currently used within the Belfast Trust, and lacked compliance with records management governance arrangements.

## **Recommendation 15**

**The Belfast Trust should review the admission policy for RABIU to ensure it complies with the trust's records management arrangements.**

The neurorehabilitation care pathway outlines the referral procedure to post-acute inpatient rehabilitation, and identifies different healthcare staff that can make a referral. Staff discussed how they made referrals, and in many trusts, this did not always follow the outlined procedure. Many referrals were still being made and discussed only by a consultant. The review team considers this is not in line with the care pathway which allows for referral by other healthcare staff.

Some trusts use a specific form for referral of patients to post-acute inpatient rehabilitation facilities, although the forms presented to the review team were different to the referral form contained within the neurorehabilitation care pathway. It was not clear whether referral forms were used for all referrals to post-acute inpatient rehabilitation. Hard copy referral forms were still being used as the computer systems within each trust were not compatible with electronic referrals.

Wherever possible, staff tried to facilitate admission to post-acute inpatient rehabilitation, with referrals being discussed on a case by case basis prior to a decision being reached. Capacity within the rehabilitation units and the patient's suitability for rehabilitation, were identified as the only barriers to admission. The neurorehabilitation care pathway sets out admission and exclusion criteria; although, staff sometimes overlooked the criteria if they considered admission would benefit the patient.

Although regional rehabilitation is provided within RABIU, by the Belfast Trust, staff from the unit confirmed that referrals from the Belfast Trust were not prioritised over other trusts. Bed availability was highlighted as a reason for delay in admission to RABIU. On average, the waiting time for admission could range between 4-8 weeks. There was some inconsistency in the waiting times reported by RABIU in comparison to the waiting times experienced by trusts referring patients to RABIU. Staff also reported that some patients were discharged home before a bed became available at RABIU. There was concern raised by staff that some patients may not be able to access all the specialist services available at RABIU.

There was limited reference to the Innisfree ward during the review. It was noted that it was very difficult to make a successful referral to the ward, as most of the beds were being utilised by long stay patients. Subsequently, Innisfree ward was generally not recognised by many staff as being part of the care pathway. Finding a suitable rehabilitation environment for patients with very complex and challenging behaviour, was cited by all trusts as being almost impossible.

Thompson House Hospital accommodates patients with longer term rehabilitation needs. Despite this, staff advised there was no waiting list for admission.

Spruce House had undergone development in line with the recommendations from the brain injury action plan. The Western Trust considered the unit had capacity and was capable of accepting more patients. The review team considered any potential increase in capacity would be to the benefit of patients, and would encourage all trusts to consider potential referrals in the future.

### **Recommendation 16**

**Trusts should consider further utilising the rehabilitation services within Spruce House if they meet the care needs of the patients.**

### **Patient Assessment and Management**

All adult post-acute inpatient rehabilitation units provided assessment and management for patients with cognitive, behavioural, physical, psychological communication, and functional difficulties. However, an area that was lacking was the provision of care for patients with significant cognitive and behavioural needs.

The review team met dedicated and enthusiastic staff working within post-acute rehabilitation units. The review did not assess the level of staffing within the units to confirm whether they were compliant with British Society of Rehabilitation Medicine standards. The focus was on the range of multidisciplinary staffing available within the units in order to provide appropriate care.

The Belfast Trust reported that all disciplines listed within the brain injury standards were represented in RABIU. Staff in RABIU informed the review team that the numbers of admitted patients with more complex needs and dependency was increasing. They highlighted that they were under-resourced, and constantly under pressure to deliver services to meet the needs of patients. It was also reported that on occasion, allied health professional (AHP) staff were relocated from RABIU to work in other areas within the Belfast Trust. The review team was concerned with this practice, as specialist, highly trained AHPs were being withdrawn from a service providing care for patients with a brain injury. This also means that funding for a regional service was potentially being utilised in other areas.

Both the Western and South Eastern trusts confirmed they had adequate staffing levels in Spruce House and Thompson House Hospital respectively. All disciplines listed within the brain injury standards were represented in their units, with the exception of clinical neuropsychology and neuropsychiatry. The Western Trust advised that their clinical neuropsychology post was vacant, and they had not been able to recruit a clinical neuropsychologist, although they had a neuropsychologist in post. The South Eastern Trust also

advised that neuropsychology was available, but not clinical neuropsychology. Some neuropsychology staff reported difficulties accessing funding to complete the Qualification in Clinical Neuropsychology (QICN), which would allow them to practice as a clinical neuropsychologist. The South Eastern Trust advised that neuropsychology staff had been funded to complete QICN. However, not all staff would be provided with funding as this was not a requirement for all neuropsychology staff.

Inadequate provision of nutrition and fluid intake was raised during the review. It was reported to the review team that some patients had experienced significant weight loss and had poor nutritional status with impairments secondary to this, upon admission to RABIU. This was more common in the moderate to severe brain injury patients who were managed in the acute hospital setting. The reasons for this are multifactorial. Staff did acknowledge that there are challenges when attempting to meet nutritional requirements; however, these challenges alone are not enough to account for the significant levels of weight loss seen in patients being admitted to RABIU. Specialist dietetic services were available in RABIU. The majority of patients admitted to RABIU, when prescribed a regime specific to their needs, gained weight. Dieticians in RABIU were available to provide advice to general dieticians in the acute hospital settings.

In all meetings with the review team, staff considered their multidisciplinary approach to care was one of their greatest strengths. From the information received, the review team considered this an area of good practice. Regular multidisciplinary meetings to discuss patient rehabilitation goals, to review progress and to plan for discharge, were taking place in all rehabilitation units. The frequency of meetings varied between units. Staff outlined the process for developing rehabilitation plans, which were goal directed and individual to each patient. Developing rehabilitation plans usually involved the patient, carers and family in discussions. Trusts confirmed that they did not have a protocol for sharing information with the patient, carers and family members; however, they stated that information was usually provided verbally.

Children's inpatient rehabilitation is only available within the Belfast Trust. The other trusts did not provide dedicated facilities for children's inpatient rehabilitation or post-acute inpatient rehabilitation

The inpatient rehabilitation services in the Belfast Trust provided assessment and management for children with cognitive, behavioural, physical, psychological communication, and functional difficulties. However, in common with adult services, an area that was lacking was the provision of specialist input dedicated to children with significant cognitive and behavioural needs.

Unlike the custom within adult services, staff advised that full multidisciplinary team meetings were not usually held within children's services, but meetings were held as required for individual children. Parental involvement was usually included during the meetings. Progress of individual children was usually discussed during weekly multidisciplinary ward rounds. Rehabilitation

plans were prepared with input from a neurodisability consultant and other multidisciplinary staff. Staff advised that they would try to involve parents at every opportunity when setting rehabilitation goals.

The review team was informed that staff were working to full capacity and it would be helpful to have staffing levels that would facilitate regular multidisciplinary meetings leading to improved planning of rehabilitation goals for individual children.

AHP therapies, such as speech and language therapy (SLT), occupational therapy (OT), and physiotherapy are available for children. Difficulties were reported in relation to the environments where therapy was provided and the level of input from therapists. There was no dedicated AHP service for children with a brain injury; however, the therapy needs of children are met by the children's therapy service within the hospital. This service covers all children's services. When demand increases in other services, this can impact on the availability for children with a brain injury.

Speech and language therapists do not have a specific treatment facility at ward level. As the ward environment was not always conducive to providing therapy, children were seen in the SLT department. However, the SLT department was not close to the ward and access was therefore difficult.

Similar problems were reported by OT. With no specific treatment facility at ward level, the early therapy input was limited for children who were unsuitable for transfer to the OT department, and therapy sometimes occurred at their bedside. The OT department was a shared facility with no quiet space for treatment.

There is a physiotherapy gym on site; however, it is a shared use facility. Staff advised that it is difficult to get a space in the gym and appointments have to be made. Noise levels in the gym sometimes impacted on the treatment session with children.

Due to the difficulties associated with providing therapy for children elsewhere, the ward environment was sometimes being used for rehabilitation purposes. Staff acknowledged this was impacting on the level of rehabilitative care that was being provided. The review team was informed that these issues have been raised with management within the Belfast Trust, and are listed on the trust's risk register.

The Belfast Trust is currently planning to build a new children's hospital. Staff informed the review team that they had made representations to the project board, to highlight the needs of neurology and brain injury services. Staff acknowledged the relatively small size of brain injury services and proposed shared rehabilitation facilities, in particular, an appropriate rehabilitation gym. However, they considered that feedback in response to their requests was not positive in relation to what could be provided. The review team recommends that the Belfast Trust includes appropriate rehabilitation facilities in the design of the new children's hospital.

Gaps in the multidisciplinary staffing arrangements within inpatient rehabilitation were reported for clinical neuropsychology and neuropsychiatry. The clinical psychology department within the RBHSC provided inpatient services to all children, not just children with a brain injury. However, not all staff had clinical neuropsychology training, and staff rotas did not enable this service to be available full time. Neuropsychiatry was not available within the inpatient setting.

#### **Recommendation 17**

**The HSC Board and trusts should review the provision and access to neuropsychiatry within the full care pathway for both adult and children's services, and take appropriate steps to ensure patients' needs for neuropsychiatry are met.**

#### **Discharge Processes**

All trusts had discharge protocols in place, and advised that either the key worker or the social worker were the primary facilitators in a patient's discharge. Carers and family members were involved at an early stage of discharge planning. However, staff reported that carers and family members involvement sometimes highlighted their reluctance to accept the option of discharge. This was based on a perception that leaving the units meant an end of quality rehabilitation. As further rehabilitation was available in the community, the review team considered that trusts needed to provide clearer information to patients, carers and family members to dispel this perception. This should be initiated from staff within the acute and post-acute inpatient settings. More in reach from CBITs may also support this workstream.

There was no intervention for early supported discharge of patients with a brain injury, highlighted by any of the trusts. None of the CBITs were resourced to provide intensive interventions in the home environment which would facilitate early supported discharge from hospital or the rehabilitation units.

There were a limited number of transfers taking place between rehabilitation units, some of which were difficult to achieve. Discharge back to an acute hospital setting was problematic and rarely happened. The majority of discharges were back into the community, under the care of a CBIT.

The Belfast and Western trusts had developed protocols for the handover of patients from rehabilitation units to CBITs. The South Eastern Trust was in the process of reviewing handover procedures and, at the time of the review, did not have an updated protocol. The handover process from rehabilitation units to CBITs worked well when it took place within trusts. However, problems were sometimes encountered when the handover was to a different trust and cases were reported of handover from rehabilitation units to general community services, rather than CBITs.

The South Eastern Trust informed the review team that they provided a discharge summary to all patients, as well as their GP and others involved in their care. The Western Trust gave the patients a copy of the discharge summary to pass on to their GP, but they did not receive a copy themselves. The Belfast Trust did not provide patients with a copy of the discharge summary. The brain injury standards state that all patients should receive a copy of their discharge summary. The review team would encourage trusts to comply with the standards, as it could assist patients with understanding the next stages of their care.

After discharge, arrangements are put in place to allow patients to continue to receive rehabilitation care as outpatients, within the regional units. This was usually additional therapy to assist patients in achieving their rehabilitation goals. The review team did not see evidence of a formal protocol for referral to this service. However, the arrangements for accessing the service were included in the CBIT's operational policies. It was unclear whether outpatient departments had copies of the operational policies and access arrangements.

Since children's inpatient rehabilitation was only provided in the Belfast Trust, there were no protocols for referrals between hospitals. Once children were admitted to the RBHSC, they would stay there until they were able to be discharged either to their home or to their local hospital to continue rehabilitation. The length of inpatient stay varied, and children were usually discharged at a point where local therapy services could meet their needs.

The Belfast Trust does have a discharge coordinator, although they cover all discharges and not just children with a brain injury. Staff reported that discharges were often delayed, as it was difficult to set up care packages quickly. Families that required additional facilities or modifications to their home were subject to delayed discharge while they were waiting for work to be completed. However, the review team was informed that some children were discharged before appropriate community services were in place. Staff proposed the possibility of a step down facility to allow beds within the RBHSC to be freed up earlier.

Staff reported that there are close links between the acute hospital setting and the community. However, they also stated there was no formal referral pathway for discharge of children back to another trust, especially in relation to children's educational needs. The review team considers that, all trusts should continue to develop and make available updated information on children's community team structures, including contact details, which can facilitate children's discharge back to trusts.

## **2.6 Standard 4: Community Services**

For many people, a brain injury is a life-long condition. Returning home following a brain injury can be difficult and readjusting to home life may be a challenge. Community brain injury teams offer specialist support and treatment, to ensure that progress made during inpatient rehabilitation is

continued once someone returns to the community. Their goal is to maximise the quality of life for patients following a brain injury. CBITs will also provide support and treatment for people with brain injury who did not require inpatient rehabilitation.

Following the 2008 review of brain injury services, criteria for referring to, and accessing CBIT services were developed. All trusts have integrated this information within their own CBIT operational policies, along with development of referral forms to facilitate access to the service. The brain injury standards envisaged that this information would be readily available in paper format and on the internet, which would also be readily accessible for families. Other than the CBIT operational policies, the review team saw little evidence of its availability, in line with the standards.

In the community setting, there are no dedicated children's brain injury teams. Children are cared for by each trust's children's community team. Children's community teams cover a wide range of illnesses, developmental disorders and disabilities. The majority of children with a brain injury are well supported within this system. The review team acknowledges that this system fits with the care of children with brain injury throughout many organisations in the United Kingdom.

Due to this model of care, there was no one within the community setting that specialised in brain injury care for children. As a result many of the requirements within the brain injury standards were difficult to apply and comply with. For referrals to community teams, there were no specific access criteria or protocols, associated with children with a brain injury; however, general referral protocols were in place. The links between the acute hospital setting and the community teams were good, with no reported issues relating to referral.

## **Patient Assessment and Management**

All CBITs provided assessment and management for patients with cognitive, behavioural, physical, psychological communication, and functional difficulties. However, an area that was lacking was the provision of care in the community for specialist input, dedicated to adults with significant cognitive and behavioural needs.

Another area highlighted to the review team was related to the long term management of patients with tracheostomies in the community. The CBITs did not have the relevant experience to appropriately care for these patients, and many of them had to be cared for in Thompson House Hospital or Spruce House.

The review team met CBIT staff from all trusts, whose enthusiasm and dedication towards their service and towards people with a brain injury, was clearly evident. They had a clear commitment to provide services to help people living with a brain injury maximise their potential. References were made to staffing levels with the teams, and the resulting pressures. In

particular, vacant posts were not being filled due to a recruitment freeze, and maternity leave was not being covered. This increased the workload and pressure on other team members had reduced their ability to provide a fully responsive service.

Staffing of CBITs, in terms of the various disciplines, was mostly in line with guidelines listed within the brain injury standards.

- The Belfast Trust had all appropriate disciplines represented, with the exception of nursing. Nursing care was provided by district nursing teams.
- The Southern Trust had all appropriate disciplines represented, with the exception of nursing. Nursing care was provided by district nursing teams.
- The Northern Trust had no physiotherapy representation within their team, but was recruiting for this post. They had a social worker within the team; however, they focused predominantly on carer issues. The majority of social work input was provided through the general community social work team.
- The South Eastern Trust advised that they have never had nursing or physiotherapy representation within their team for a particular sector. These services have always been provided by community nursing and physiotherapy when required. They also advised that clinical neuropsychology was not available.
- The Western Trust had no speech and language therapy within the team; however, access to this service was through community outpatients.

In most trusts, there was no direct involvement from the disciplines of rehabilitation medicine, neuropsychiatry and dietetics within the CBITs; however, all trusts had referral links to these services and they could be accessed when required. The South Eastern Trust advised that a rehabilitation medicine consultant did provide input in the CBIT.

In relation to children, all trusts reported that children's community teams provided assessment and management for patients with cognitive, behavioural, physical, psychological communication, and functional difficulties. However, an area that was lacking was the provision of care in the community for specialist input, dedicated to children with significant cognitive or behavioural needs.

There was evidence of good multidisciplinary working within the children's community teams, although there was limited specialist knowledge in relation to brain injury. The teams had representation from most of the disciplines listed within the brain injury standards. Clinical neuropsychology was absent from all trusts except the Belfast Trust. The Belfast Trust also listed nursing and social work as disciplines not represented within the children's community team; however, referral to these services was possible.

All children's community teams had access to a dietetics service. There was generally no access to the disciplines of rehabilitation medicine and neuropsychiatry, although the South Eastern Trust has access to rehabilitation medicine. Specialist advice in relation to brain injury was available from the

Children's ABCS. Staff in all trusts commented on the benefits of this service and stated that it was very responsive.

A consequence of the children's community model of care was that children with a brain injury, after discharge, were not always under the care of neurosciences services. Some children could remain under the care of other medical specialties, such as general paediatrics, surgery, infectious diseases or haematology. Some of these specialties did not have access to clinical psychology outpatient services.

The review team was informed that unless a child has been admitted, they may not receive access to the full range of community services. It was noted that therapies were provided to all specialties within children's services; however, there were no specific specialist therapies for brain injury. There were often long waiting lists for access to therapy, and appointments were often prioritised.

### **Role of Key Workers**

A key worker is assigned to each patient to take a lead role and provide support to patients, carers and family members. The majority of people from focus groups were unfamiliar with this role and were unsure as to who the key worker was. However, all trusts reported that they had assigned a key worker to each patient. It subsequently emerged during discussions with staff that the key worker may change throughout a patient's journey. Trusts had taken the approach that the lead therapist would be the designated key worker, as they would be the person most in contact with the patient. The review team considered this to be a practical approach, but considered that it may also be the reason patients, carers and family members were unclear about the key worker role, as the lead therapist role may change a number of times within a patient journey. It is advised that trusts clearly explain the role of the key worker to patients, carers and family members, and that they are made aware of the identity of their key worker throughout the process.

#### **Recommendation 18**

**Trusts should ensure that all families are aware of their key worker and are kept informed of any changes.**

### **Rehabilitation plans**

A rehabilitation plan had been developed for all patients. Plans were goal-directed, which required input from the patient, carers and family members. Some trusts had included their rehabilitation plan template in their CBIT operational policy. During meetings with the review team, staff outlined the different methodologies they used for developing rehabilitation plans. Staff reported that rehabilitation plans were reviewed and updated regularly to reflect the changing needs of the patient. The frequency of review was dependent upon the progress of the patient. The review team was confident

that this process was being carried out as stated and had the flexibility to be changed in line with the needs of the patient.

All trusts advised that patients were provided with copies of their rehabilitation plans. Similarly, all trusts, with the exception of the Western Trust, advised that copies of rehabilitation plans were forwarded to the patient's GP and other appropriate healthcare professionals. The review team considered that it was important that trusts continue to ensure that copies of rehabilitation plans are given to patients and forwarded to other relevant professionals as a matter of good practice.

Specific brain injury rehabilitation plans are not prepared for children. Each trust completed different development plans, such as, family support plans, or plans aligned to the UNOCINI Framework<sup>11</sup>. Copies of plans were not usually given to the families, but were shared with them. The Northern Trust advised that children's plans were provided to parents upon completion. The plans were not forwarded to the child's GP, but they were kept informed of them by correspondence.

#### **Recommendation 19**

**Trusts should ensure that copies of rehabilitation plans are forwarded to all appropriate health professionals, and provided to the patient, their carers and family where appropriate.**

#### **Links with Statutory and Voluntary Organisations**

CBITs have developed close working relationships with various statutory, voluntary and charitable organisations, to assist with the provision of services to people with a brain injury. All trusts had service level agreements (SLAs) with some of the voluntary and charitable organisations. Trusts referred people with a brain injury to those organisations with which they had an SLA; however, they also made people aware of the services provided by other voluntary and charitable organisations.

Formal contractual arrangements governed the safety and quality of the services being provided. These included contract review meetings, formal contract update and compliance meetings, and regular meetings with CBITs. Organisations providing commissioned services to submit monitoring statistics for the service, including activity levels, validity against the agreed targets, incidents, accidents, near misses, complaints and vulnerable adult issues. CBIT staff also monitored the quality of services through feedback from people with a brain injury, carers and family members.

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<sup>11</sup> UNOCINI – Understanding the Needs of Children in Northern Ireland - [http://www.dhsspsni.gov.uk/microsoft\\_word\\_-\\_unocini\\_guidance\\_revised\\_june\\_2011\\_inc\\_mh\\_domain\\_elements.pdf](http://www.dhsspsni.gov.uk/microsoft_word_-_unocini_guidance_revised_june_2011_inc_mh_domain_elements.pdf)

In the Southern Trust, CBITs worked with the Cedar Foundation to train staff from Cedar to carry out assessments of people with a brain injury. The review team considered this collaboration was an area of good practice.

Children's community teams have developed working relationships with various statutory, voluntary and charitable organisations, for the provision of services to children with a brain injury. The management of these arrangements is consistent with the arrangements outlined earlier for adult services.

### **Carers' Assessments**

All trusts reported that they routinely offer assessments to carers and family members. However, there was often a low uptake of the carers assessment, as many people did not perceive themselves as being a carer, or believed they were coping well at the time they were initially offered support.

Assessments are also offered throughout the rehabilitation process, as and when circumstances change. Trusts submitted evidence of the information that was available for carers. Support available to carers varied between trust, and generally included education sessions about brain injury, referral to counselling services, complementary therapies, carer grants and short break care.

All trusts advised that they routinely offer carers assessments via the UNOCINI Carers Assessment Guidance, to parents and family members. Again, it was reported that there was often a low uptake for assessment, as many parents did not perceive themselves as having specific needs as a carer, or believed they were coping at the time they were initially offered support. Assessments are also offered throughout the rehabilitation process as and when circumstances change. Trusts submitted evidence of the information available for carers, which varied between trust, and generally included the same range of information as for carers of adults with a brain injury.

### **Discharge Processes from Community Teams**

Discharge from community brain injury services usually occurred when it was agreed that all rehabilitation goals had been met. Other criteria, such as transfer to another trust area, not complying with the rehabilitation plan, or lack of engagement, were considered as reasons for discharge. Trusts had no formal discharge policy, but information and criteria for discharge were included within CBIT operational policies.

Trusts advised that the care provided by CBITs was not usually time limited, and would continue as long as there were clear rehabilitation goals and progress was being made towards those goals. Staff also reported that people with a brain injury could be re-referred to the service in the future. However, this was dependent upon whether further rehabilitation could be achieved and the re-referral had to be related to brain injury.

The sources for re-referral differed between trusts. While all trusts accepted a re-referral from a healthcare professional, only a few trusts accepted self-referrals. Information about the re-referral process, including criteria for re-referral, was provided to patients at the time of discharge.

There were no discharge policies for the management of children within brain injury services, or for children with brain injury transitioning to adult community brain injury services. The ongoing care and subsequent transition fall under general policies for children with complex health needs within children's services. However, information about transition arrangements is included in adult CBIT operational policies. The Southern Trust advised of plans to establish a transition team, although it would not be solely for children with a brain injury. Where children with a brain injury are known, CBITs engaged with the children's community teams to help facilitate the transition. To ensure effective transition from children's to adult services, the review team considers that transition arrangements should be communicated more robustly to children's community teams.

#### **Recommendation 20**

**Trusts should ensure that transition arrangements to adult services are properly communicated to children's community teams.**

### **2.7 Standard 5: Continuing Care and Support**

Through the work of RABIIG, an Acquired Brain Injury Adult Community Care Pathway and a Regional Brain Injury Services Guide were produced. Trusts advised that both these documents were forwarded to GP practices, community nurse services and voluntary and charitable organisations. They were also hosted on the HSC Board website, and copies were available in rehabilitation units.

The documents outlined the arrangements for care, following discharge from the acute hospital setting and rehabilitation units, as well as discharge from the community brain injury services. However, there is limited information in relation to the long term care of people after discharge from community brain injury services.

In relation to long term care, only the Western Trust considered this to be a responsibility of the CBIT. The social worker within the CBIT has responsibility for annual reviews. The other trusts advised the review team that when rehabilitation goals had been achieved, ongoing long term care would become the responsibility of the core teams in physical disability, mental health or older person's directorates. Within these directorates, people with a brain injury should receive an annual review. Staff from the CBITs should then have an input into annual reviews.

It was noted that re-referral to the brain injury service was possible. This could be initiated by any healthcare professional, or in some trusts, by self-referral.

Trusts reported that care packages were available for people living with a brain injury. Care packages included sitting services, residential placements, day care opportunities, and access to voluntary and charitable groups. The review of care packages within trusts was part the overall care management review process. The service providing the ongoing care usually led the review process.

The ongoing review of a person's accommodation arrangements was carried out by CBITs, as long as they were in receipt of services from a CBIT. Once the long term care transferred to another service, the review of accommodation arrangements became their responsibility. However, staff from the CBITs did have an input into the reviews. Although a review of accommodation arrangements was undertaken, the recommendations arising from the review were not always progressed/ guaranteed.

As the responsibility for the long term care of people with a brain injury usually transferred to another service, the review team considered that many of the criteria outlined within this standard did not fall within the remit of CBITs. Therefore it was difficult to assess the application of this standard.

There are no brain injury specific care pathways for the continuing care and support of children with a brain injury. All care and support is provided within the general children's services by children's community teams. The reviews of care packages and short break packages are carried out via the Family Support Review Plan within the UNOCINI framework.

## **2.8 Standard 6: Information for Patients, Families and Carers**

The provision of information is an important aspect of patient care, as it helps the patient to understand their condition, what is involved in their treatment, and how they might be affected in the future. Trusts had a variety of different types of information available for patients to better inform them about their brain injury. However, some staff still considered that there was not enough information available for patients, carers and family members. Although information was not readily available in alternative formats, trusts confirmed that it could readily be made available upon request.

Staff informed the review team that information about brain injury was provided to patients, carers and family members at all stages of the patient journey. This was consistent with the views of some of the people who attended focus groups, but not all of them.

During focus groups, some people related that they had received a lot of information. Although they appreciated this, many felt that it was too much information, and looking back, felt that it was provided at the wrong time.

Some advised that they only received basic information which they felt was not adequate. A number of people did not receive any information and had to find it themselves, either from the internet or from voluntary or charitable organisations.

The review team was confident that staff were providing people with information about brain injury, but considered that the quantity and timing of the delivery of the information could be improved. The review team recommends that trusts review the way information is provided, to ensure it maximises the benefits for patients, carers and family members.

Trusts also provided patients, carers and family members with information about support groups, outreach groups, self-help groups, and services provided by voluntary and charitable organisations.

RABIIG had produced a Regional Brain Injury Services Guide, which was distributed to GP practices, community nurse services and voluntary and charitable organisations. People who attended focus groups were not aware of the existence of a regional guide.

During the review, it became clear that the regional guide was not being used or referenced on a regular basis. Many staff stated that they had little confidence in the regional guide, as it was too generic and it lacked the individual information about brain injury that people required. Some staff informed the review team that they would not generally give it out. It was not evident which organisation had responsibility for updating the information contained within the guide; however, it was obvious that it had not been updated since its development and some of the information was now out of date. The review team considered that the regional guide was potentially a useful resource for people with a brain injury; however, it needed to be updated in relation to the accuracy and usefulness of its content.

#### **Recommendation 21**

**The HSC Board and trusts should review the accuracy and usefulness of the information in the regional guide to determine if it is beneficial to people with a brain injury, their carers and family members. Other stakeholders should be involved in the review.**

Trusts advised that feedback was obtained from people with a brain injury, their carers and family members in relation to the information provided for them. However, this occurred on an ad-hoc basis for specific things, rather than on a regular or consistent basis.

Trusts have a range of information specific to brain injury available for children and their parents. Some of the information was presented in an age appropriate format and although only some information was available in alternative formats, it could be provided when requested.

Staff in all trusts provided parents and carers with information about support networks and community groups, although the availability of groups specific to children's brain injury was limited. Parents were also advised of relevant services provided by trusts and in local areas, provided by voluntary and charitable organisations. The review team considered that staff were providing parents with information about brain injury, but considered that the timing of the delivery of the information could be improved. The review team recommends that trusts review the way information is provided, to ensure it maximises the benefits to children, carers and family members.

No evidence was presented that demonstrated that families were being involved in reviewing the content, timing or appropriateness of the information being provided for them.

#### **Recommendation 22**

**For both adult and children's services, trusts should review the way in which information is provided, to ensure that it maximises the benefits for patients, carers and family members.**

## **2.9 Standard 7: Accommodation Provision**

### **Adults with a Brain Injury**

Appropriate accommodation maximises the potential for rehabilitation and helps to maintain the functional gains achieved by the patient. All trusts assessed the accommodation needs of people living with a brain injury in preparation for discharge. As part of this process, rehabilitation units have adapted areas within each facility to mimic the home environment. Patients and their families used this facility as part of the discharge process, to assess the needs of patients and also to let families and carers be aware of the responsibilities they now faced. Ongoing accommodation assessments were also carried out by the CBITs as part of multidisciplinary assessments, or when the needs of the person living with a brain injury changed.

Trusts did not provide specific accommodation for people living with a brain injury. However, they worked in partnership with other organisations, such as, the Northern Ireland Housing Executive, the Cedar Foundation, housing associations and private landlords to provide the most suitable accommodation for them. Residential homes and nursing homes were also used to care for people living with brain injuries.

The lack of accommodation placements in the community for patients requiring long term tracheostomies was a significant gap. Following discharge from the acute hospital setting, these patients were reliant on care within one of the three post-acute specialist units. Each unit is staffed for a finite number of acute tracheostomy beds. When these beds were filled, patients remained in them for inappropriately long periods of time, as there was no suitable alternative community accommodation and care package for this complex

group. The Southern and Western trusts had worked with nursing homes to provide training for staff in the care of patients requiring long-term tracheostomies. However, these places were limited.

The review team was made aware of many cases where the lack of supported living accommodation has resulted in some people living with a brain injury being placed in facilities that may not meet their assessed needs. In the absence of suitable alternatives, younger people were being inappropriately placed in residential or nursing homes. Staff advised that they had also encountered organisations that promoted their ability to provide care for people living with a brain injury. However, it was subsequently discovered that staff within these organisations lacked the appropriate training and expertise, and were often unaware of the extent of the needs of people living with a brain injury.

All trusts reported that providing care for adults with extremely challenging behaviour or with complex needs was a major issue. Despite trying to find appropriate care locally, several patients have been forced to access care outside Northern Ireland. With the exception of the Southern Trust, all trusts had commissioned care placements outside of Northern Ireland. The Southern Trust advised that where cases had been identified, they sought funding for bespoke housing built around their specific needs, or negotiated an enhanced package of care through existing residential or nursing contracts.

For patients in out of area placements, the CBITs continue to be involved in their review process. Key workers participate in multidisciplinary reviews, and are provided with regularly updated clinical assessments and progress reports.

The HSC Board highlighted that the provision of care associated with out of area placements, was their biggest challenge. They advised that current spending for out of area placements was approximately £1.75 million per annum. The HSC Board advised that RABIIG had completed a scoping exercise to determine the scale of the need, and they had sought funding from DHSSPS to address this. They advised that no additional funding was available, and indicated that no further progress could be made on this issue in the absence of additional funding. Despite the scoping exercise, the HSC Board confirmed that no costing for the care of these patients in Northern Ireland had been undertaken. It could not be confirmed whether the cost of providing appropriate care in Northern Ireland was more or less expensive than the cost of commissioning services from outside Northern Ireland.

A central theme of the brain injury standards, Transforming Your Care<sup>12</sup>, and Quality 2020<sup>13</sup> is to ensure that patients are provided with the right care, in the right place, at the right time. The review team considered this theme was not

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<sup>12</sup> Transforming Your Care - <http://www.transformingyourcare.hscni.net/wp-content/uploads/2012/10/Transforming-Your-Care-Review-of-HSC-in-NI.pdf>

<sup>13</sup> Quality 2020 - [http://www.dhsspsni.gov.uk/quality\\_2020\\_-\\_a\\_10-year\\_quality\\_strategy\\_for\\_health\\_and\\_social\\_care\\_in\\_northern\\_ireland.pdf](http://www.dhsspsni.gov.uk/quality_2020_-_a_10-year_quality_strategy_for_health_and_social_care_in_northern_ireland.pdf)

being met in relation to out of area placements, and that no meaningful work had been undertaken to resolve this issue. It is recommended that an appropriate costing exercise is undertaken to determine the cost of providing care for adults with extremely challenging behaviour or with complex needs within Northern Ireland, and a comparison made with the cost of commissioning services outside Northern Ireland. The review team would recommend that all options of care should be considered.

### **Children with a Brain Injury**

None of the trusts provided specific accommodation for children with a brain injury. It was considered that children with a brain injury would be cared for within the parental home. Trusts concentrated their efforts to support the care of the child at home. Alternative care options were available in some trusts, such as, short break care, nursing care, foster care and the Iveagh Centre<sup>14</sup> in the Belfast Trust.

Care needs assessments were carried out in all trusts. These were conducted in line with both the UNOCINI framework and the Integrated Care Pathway for Children with Complex Physical Healthcare Needs<sup>15</sup>. Depending upon the complexity of the assessment, they were conducted by an OT or by multidisciplinary teams.

All trusts reported that providing care for children with extremely challenging behaviour or with complex needs was a major issue. Some trusts had commissioned out of area placements for children with such needs. The review team considered that the costing exercise associated with out of area placements should include children within its remit.

#### **Recommendation 23**

**The HSC Board should conduct an appropriate costing exercise to determine the cost of providing care, for adults and children with extremely challenging behaviour or complex needs, within Northern Ireland. The costing should be compared with the cost of commissioning services outside of Northern Ireland, and appropriate action taken based on the findings.**

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<sup>14</sup> The Iveagh Centre provides acute, short term, multidisciplinary inpatient assessment and treatment for children and young people up to the age of 18 who have a learning disability, additional mental health difficulties, and who may display associated complex patterns of behaviour.

<sup>15</sup> Integrated Care Pathway for Children with Complex Physical Healthcare Needs - [http://www.dhsspsni.gov.uk/integrated\\_care\\_pathway-july09.pdf](http://www.dhsspsni.gov.uk/integrated_care_pathway-july09.pdf)

## **Section 3 – Conclusions and Recommendations**

### **3.1 Conclusions**

The adult brain injury services provided by the trusts are predominantly community based. There are no specific services for adults with a brain injury within the acute hospital setting, although post-acute inpatient rehabilitation is provided.

Following the 2008 review, staff from brain injury services were brought together within RABIIG, under the chairmanship of the HSC Board. RABIIG provided the strategic direction for brain injury services and its achievements in service improvement included development of brain injury standards and development of a number of care pathways for brain injury patients.

The review team considers that the dissolution of RABIIG and incorporation of its responsibilities into the Physical and Sensory Disability Strategy, rather than maintaining an appropriate regional structure for brain injury, has been detrimental to the future development of the services.

Although trusts had embraced the brain injury standards and were implementing many of their requirements, it was evident that a joint approach between trusts was not being undertaken. The review team identified that an appropriate regional structure was required to drive strategic direction and provide meaningful service improvements for brain injury services.

The current organisation of brain injury services and the focus of the brain injury standards have had an influence on the interface arrangements within and between trusts. The main focus of the brain injury standards and action plan is on the care of medically stable patients in the post-acute phase of treatment, care and support. This limits the impact and subsequent use of the standards within the acute hospital setting, which the review team considered was reflected during the review.

Patients presenting to the ED are assessed and treated according to the severity of their injury. Patients with a moderate to severe brain injury were admitted to general medical or surgical wards in acute hospitals, or to the neurosciences wards within the Belfast Trust. However, it was not uncommon for some patients to be admitted to other wards. Patients with a mild brain injury were usually discharged. Although patients with a brain injury were being identified, the onward referral to community brain injury teams for follow up of patients with a mild brain injury was not always happening. Some documents outlined in the brain injury standards were not available in the ED, and referral protocols were not always being used. The review team considered that identification of patients would be improved if all trusts followed the model of establishment of a role linked to specialist brain injury services, to identify and facilitate the pathway for patients with a brain injury.

Specialist multidisciplinary therapeutic interventions were only available on neurosciences wards in the Belfast Trust. Patients with ABI and multiple

comorbidities (e.g. poly-trauma), admitted to wards outside of neurosciences were unlikely to have received any specialist therapeutic interventions or treatment for their brain injury.

Post-acute inpatient rehabilitation was provided at four units across Northern Ireland. Protocols and policies were available for referral to these rehabilitation units, which included access and exclusion criteria; however, these procedures were not always being followed.

Throughout the review, the review team met dedicated and enthusiastic staff working within post-acute rehabilitation units. The range of disciplines listed within the brain injury standards were represented in RABIU. Spruce House and Thompson House Hospital reported that all disciplines listed, with the exception of clinical neuropsychology and neuropsychiatry were represented.

Regular multidisciplinary meetings to discuss patient rehabilitation goals, review progress and plan for discharge, were taking place in all rehabilitation units. Development of rehabilitation plans were goal directed and usually involved the patient, carers and family in the discussions. The review team considered this to be a particular strength.

Protocols for the handover of patients from rehabilitation units to CBIT were available. The handover process from rehabilitation units to CBIT worked well when it was within trusts; however, some problems were encountered when the handover was to a different trust. This resulted in some patients being referred to general community services rather than CBIT.

All trusts had CBITs, staffed by people whose enthusiasm and dedication towards both their service and patients with a brain injury was clearly evident. Staff complements of community teams were mostly in line with the disciplines listed within the brain injury standards. Where there were gaps, access to these disciplines was available elsewhere in the trust.

CBITs had developed close working relationships with various statutory, voluntary and charitable organisations, in order to provide appropriate services for people with a brain injury.

Trusts had developed protocols for the discharge of patients from community brain injury services, which usually occurred when all rehabilitation goals had been met. Trusts had no formal discharge policy, but information and criteria for discharge were contained within CBIT operational policies. Arrangements for re-referral were in place and were provided to patients upon discharge.

The long-term care and follow up of people with a brain injury generally fell outside of the remit of the CBITs in most trusts. This usually became the responsibility of general community services. Patients could re-access specialist support where this was indicated.

Information about brain injury was provided to patients, carers and family members at all stages of the patient journey. The review team considered

that information was being provided; however, the timing and method of delivery needs to be reviewed, to ensure it maximises the benefits to the patients, carers and family members.

Trusts did not provide specific accommodation for people living with a brain injury. However, they worked in partnership with other organisations, such as the Northern Ireland Housing Executive, the Cedar Foundation, housing associations and private landlords to provide the most suitable accommodation for them. Residential homes and nursing homes were also used to care for people living with brain injuries, although this was not always appropriate for younger people.

The accommodation provision for the care of patients requiring long-term tracheostomies was an area that needs to be looked at.

A distinct gap within the service was the provision of appropriate care for adults with extremely challenging behaviour or with complex needs. Such cases were often treated in facilities outside Northern Ireland. The review team considered that the provision of appropriate care within Northern Ireland needed to be reviewed, properly costed, and compared with the cost of commissioning such services from outside the country.

In Northern Ireland there is no separate brain injury service for children in either the community or in the acute hospital setting. Children with a brain injury are cared for within the relevant specialty of children's services, which focuses on the child and not the condition. This model of care is consistent with provision of care for most conditions. As trusts advised that numbers were small, the review team did not consider that the development of a specific children's brain injury service in the community was necessary; however, the team considered that community teams would benefit from more readily available specialist advice.

With no specific brain injury service for children, the review team was unable to identify where responsibility lay for providing the strategic direction for this area of care. During the time of RABIG, children's brain injury services had also benefitted from work undertaken by this regional group.

Within children's services, pathways, protocols, and guidance for the transfer and transition of children between services were in place; however, these are generic documents and not specific to brain injury. Although there was a specific brain injury care pathway for children and young people, it was unclear as to how extensively this was being used, if at all.

The review team spoke with key members of staff in each trust that have taken a particular interest in children's brain injury. The review team considered that their drive and enthusiasm was contributing to assuring the quality of care being provided.

There are no dedicated facilities for children's inpatient rehabilitation or post-acute inpatient rehabilitation in Northern Ireland. The only service for children's inpatient rehabilitation is within the Belfast Trust.

Children presenting at an ED with a potential brain injury are assessed and treated according to the severity of the injury. Children with a mild brain injury are usually discharged or admitted to a children's ward for observation. Children with a moderate to severe brain injury are usually transferred to Paul Ward in the Royal Belfast Hospital for Sick Children, within the Belfast Trust.

The Paul Ward accommodates a variety of specialities and so is not considered by the review team to be an entirely suitable environment for neurology patients. This issue needs to be addressed in the new children's hospital.

The review team considered that there were a number of significant gaps in the documentation that had been developed in children's brain injury services, such as, the early acute management of children with a brain injury, post traumatic amnesia assessment, and referral protocols.

Referral should be made to a health visitor or social worker, where appropriate, for possible follow up after discharge; however, children who were not admitted were less likely to be referred to community services for follow up.

Although AHP therapies were available during inpatient rehabilitation, the arrangements for the provision of these services was not ideal. The provision of appropriate inpatient rehabilitation must be included in the planning of the new children's hospital. Clinical neuropsychology and neuropsychiatry were reported to the review team as being gaps in the multidisciplinary staffing arrangements within inpatient rehabilitation. The clinical psychology department within the RBHSC provided limited cover in this area.

Discharge links within the Belfast Trust, between the acute hospital setting and the community were good; however, discharge back to other trusts could on occasion be problematic.

In the community setting, there are no dedicated children's brain injury teams, with children being cared for within each trust's children's community team. As a consequence of this model of care, there was no specific individual within the community setting that had a specialist remit for brain injury care. This is also the case when considering the long term care of children with a brain injury.

Despite the development of a specific brain injury care pathway for children and young people, the management of care within the community setting was governed by general children's protocols.

The make-up of community teams was generally in line with the requirements outlined in the brain injury standards. Although some disciplines were not

represented, referral to these services within each trust was possible. Provision of clinical neuropsychology services for children needs to be improved.

Community teams could access specialist brain injury advice from the regional Children's ABCS. This was a valuable service and should be further developed if possible.

There were fewer voluntary and charitable organisations that provided services specifically for children with a brain injury. Good working relationships were reported between these organisations and the trusts. These relationships need to be maintained for the benefit children and their families.

A range of information, specific to brain injury, was available for children and their parents. This was provided at various stages of the child's journey; however, the timing and method of delivery needs to be reviewed, to ensure it maximises the benefits to the children, carers and family members.

Trusts did not provide specific accommodation for children living with a brain injury. Trusts concentrated their efforts on supporting the care of the child at home.

A distinct gap was the provision of an appropriate service for children with extremely challenging behaviour or with complex needs. Such cases were being treated in facilities outside of Northern Ireland. The review team considered this issue needed to be included in the review recommended for adult services.

The report makes 23 recommendations for improvement to the services providing care for children and adults with a brain injury.

RQIA wishes to thank the management and staff from the trusts and the HSC Board for their cooperation in taking forward this review.

### 3.2 Summary of Recommendations

	<b>Recommendation</b>
1	The HSC Board and trusts should meet to discuss establishment of an appropriate regional structure to facilitate the continued development and improvement of brain injury services.
2	Where not already established, trusts should consider development of a role linked to specialist brain injury services, to identify and facilitate the pathway for people with a brain injury in acute and general inpatient wards.
3	Trusts should review their liaison arrangements between the brain injury services and mental health services, to ensure there is integrated working between services.
4	The capacity of the children's acquired brain injury consultation services should be reviewed to determine if it is sufficiently resourced to meet increasing demand for their services, and appropriate action taken based on the findings.
5	Trusts should develop appropriate information about community team structures for both children and adult services. This information should be shared within and between trusts, to facilitate discharge back to the community setting.
6	Appropriate training on dealing with patients with a brain injury should be provided for generic community teams and staff working on non-specialist brain injury wards.
7	The Belfast Trust, in conjunction with the HSC Board should evaluate its relationships with voluntary and charitable organisations providing services to children with a brain injury, their families and carers, to ensure a coordinated approach to the provision of services.
8	The HSC Board in conjunction with trusts should develop appropriately defined data sets and audit tools to support a system of audit against the quality indicators contained in the brain injury standards.
9	The HSC Board and trusts should use the Personal and Public Involvement Standards as the basis on which to involve patients, carers and family members in the development of brain injury services.
10	Trusts should develop and implement a written protocol for the assessment of post-traumatic amnesia in both children and adults, for use within Emergency Departments.
11	Trusts should develop protocols for the management of brain injury patients accommodated in general wards. The protocols should include liaison arrangements with specialist multidisciplinary teams and brain injury services for advice and management of these patients.

12	Trusts should develop protocols for the management of brain injury patients accommodated in neurosciences wards. The protocols should include rehabilitation planning, discharge and liaison arrangements with community brain injury teams.
13	Trusts should review their process for follow up of children with a mild brain injury.
14	The Belfast Trust should prioritise the provision of (i) a suitable ward environment for neurology patients, and (ii) acute neurological rehabilitation facilities within the new children's hospital.
15	The Belfast Trust should review the admission policy for RABIU to ensure it complies with the trust's records management arrangements.
16	Trusts should consider further utilising the rehabilitation services within Spruce House if they meet the care needs of the patients.
17	The HSC Board and trusts should review the provision and access to neuropsychiatry within the full care pathway for both adult and children's services, and take appropriate steps to ensure patients' needs for neuropsychiatry are met.
18	Trusts should ensure that all families are aware of their key worker and are kept informed of any changes.
19	Trusts should ensure that copies of rehabilitation plans are forwarded to all appropriate health professionals, and provided to the patient, their carers and family where appropriate.
20	Trusts should ensure that transition arrangements to adult services are properly communicated to children's community teams.
21	The HSC Board and trusts should review the accuracy and usefulness of the information in the regional guide to determine if it is beneficial to people with a brain injury, their carers and family members. Other stakeholders should be involved in the review.
22	For both adult and children's services, trusts should review the way in which information is provided, to ensure that it maximises the benefits for patients, carers and family members.
23	The HSC Board should conduct an appropriate costing exercise to determine the cost of providing care, for adults and children with extremely challenging behaviour or complex needs, within Northern Ireland. The costing should be compared with the cost of commissioning services outside of Northern Ireland, and appropriate action taken based on the findings.

## **Appendix 1 - Abbreviations**

ABI	- Acquired Brain Injury
AHP	- Allied Health Professional
Belfast Trust	- Belfast Health and Social Care Trust
CBIT	- Community Brain Injury Team
Children's ABCS	- Children's Acquired Brain Injury Consultation Service
DHSSPS	- Department of Health, Social Services and Public Safety
ED	- Emergency Department
HSC	- Health and Social Care
NICE	- National Institute for Health and Care Excellence
Northern Trust	- Northern Health and Social Care Trust
OT	- Occupational Therapy
PHA	- Public Health Agency
PPI	- Personal and Public Involvement
PSD	- Physical and Sensory Disability Strategy
QICN	- Qualification in Clinical Neuropsychology
RABIIG	- Regional Acquired Brain Injury Implementation Group
RABIU	- Regional Acquired Brain Injury Unit
RQIA	- Regulation and Quality Improvement Authority
SLA	- Service Level Agreement
SLT	- Speech and Language Therapy
South Eastern Trust	- South Eastern Health and Social Care Trust
Southern Trust	- Southern Health and Social Care Trust
UKROC	- United Kingdom Rehabilitation Outcomes Collaborative
Western Trust	- Western Health and Social Care Trust





The **Regulation** and  
**Quality Improvement**  
Authority

The Regulation and Quality Improvement Authority  
9th Floor  
Riverside Tower  
5 Lanyon Place  
BELFAST  
BT1 3BT

Tel: (028) 9051 7500  
Fax: (028) 9051 7501  
Email: [info@rqia.org.uk](mailto:info@rqia.org.uk)  
Web: [www.rqia.org.uk](http://www.rqia.org.uk)