THE ACQUIRED BRAIN INJURY STRATEGY FOR GRAMPIAN.

2011-2016

January 2011.

Contents

1. Executive Summary

The human brain controls all our thoughts, feelings and actions, both voluntary and involuntary and when it is damaged the consequences are often complex and variable. Acquired brain injury (ABI) often leads to a mixture of physical, cognitive, communicative, emotional and behavioural changes with profound consequences for the individual and their family[1]. These difficulties require support and rehabilitation from services who understand the specialist needs for people with acquired brain injury.

The **purpose of this strategy** is to improve the lives of people with an acquired brain injury and their carers in Grampian.

Consultation with service users, their families and professionals working with people with acquired brain injury has identified the following top priorities:

The appointment of a lead clinician or senior manager with responsibility for the planning and review of acquired brain injury services.

Development of a Community Acquired brain injury Team including continued funding for Transitions.

It is recognised that in the current political climate and financial status of NHS Grampian and Aberdeen city, Aberdeenshire and Moray councils, that additional funding is not available. Considering this, a number of suggestions for change and development are made within this document, including:

- Support the existing local managed care networks to continue to develop their role including strengthening the link between local acquired brain injury managed care networks (local MCNs) and Grampian Managed Care Network for Brain Injury.
- Increase awareness of local MCNs among professionals working with people with acquired brain injury
- Improve opportunities and access to support for carers of people with acquired brain injury.
- Increase and improve engagement with service users and carers.
- Increase range of opportunities for respite and facilitate access to these services for people with acquired brain injury and their families.
- Compile list of training currently running in Grampian and eligibility for access.
- Review Scottish Acquired brain injury Network / Quality Improvement Scotland standards, identify those not met and form a plan to work towards meeting standards.

The contributors to the Grampian Brain Acquired Brain Injury Strategy 2011-2016 are listed in appendix a.

[1] Traumatic Acquired brain injury in Adults. Standards. Scottish Acquired brain injury Managed Clinical Network.

2. Progress and Developments since Grampian Acquired brain injury Strategy 2004-2010

The Grampian Brain Injury Strategy **2004-2010** had three main aims:

- Investment in a dedicated brain injury team to work across Grampian providing specialist support for people with acquired brain injury and training for both carers and paid workers who support people with acquired brain injury.

- Support for a lottery application submitted by Momentum for community based workers to support people with acquired brain injury.

- The working together of all the agencies involved in developing the strategy as a Grampian brain injury network which will be progressed by a Grampian wide brain injury seminar.

Achievements since 2004

- Employment of two acquired brain injury workers (Transitions) initially through lottery funding.

- Establishment of the Grampian Managed Care Network for Brain Injury with the aims of bringing together voluntary sector, health and social service workers across Grampian. *(appendix b)*

- Establishment of monthly local clinical meetings of professionals to facilitate communication and co-ordination of services to people with acquired brain injury (local acquired brain injury MCNs).

- Two seminars to bring together health, council, voluntary sector workers and patients and carers to discuss progress and ways forward in acquired brain injury.

- Opening of Craig Court, a specialist residential service for rehabilitation of people with acquired brain injury. Patient feedback records a high level of satisfaction with this service.

- Increased involvement of users and carers in planning services

Summary

The primary aim of the Grampian Acquired brain injury Strategy 2004-2010, the establishment of a community acquired brain injury team has **not** been achieved. However the two secondary aims, the funding of acquired brain injury workers (Transitions) and the establishment of a managed care network for acquired brain injury in Grampian have been achieved. Acquired brain injury services have been developed in other areas and professionals working with people with acquired brain injury have taken steps towards better communication and co-ordination.

3. Definitions and Epidemiology

- Acquired brain injury is **defined** as damage to the brain acquired at some point after birth, but not due to any degenerative disease. It includes damage caused by traumatic injury, lack of oxygen or infection but, for the purposes of this document, does not include stroke.

- The **consequences** of acquired brain injury are wide ranging and include -

  - physical difficulties such as mobility and co-ordination problems.
  - cognitive difficulties including problems with memory, organising and planning, decision making, and insight.
  - communication difficulties
  - emotional problems including anxiety, depression, and post traumatic stress.
  - behavioural problems including inappropriate social behaviour, aggression, and inappropriate sexual behaviour.

- The **complex and long term disabilities** caused by acquired brain injury have **profound implications** for families and carers, as well as for those with an acquired brain injury themselves. It is often only after a period of time that these become apparent, particularly in mild or moderate cases.

- There are no precise **statistics** on the prevalence of people with acquired brain injury in the Grampian area. McMillan[2] suggested -

  - 150 people per 100,000 will be moderately or severely disabled as a result of acquired brain injury.
  - 350 people per 100,000 each year would benefit from rehabilitation following acquired brain injury.

- Grampian's **population** is 546,500, suggesting annual figures of approximately -

  - 820 severely/moderately disabled.
  - 1913 likely to be in need of rehabilitation.

- In 2003 a total of 814 people were admitted to hospitals in Grampian, including, Aberdeen Royal Infirmary with head/acquired acquired brain injury. The **level** of acquired brain injury was classified as follows -
  - 80% mild (up to 2 nights in ARI) = 670 people.
  - 10% moderate (up to 7 nights in ARI) = 81 people.
  - 11% severe (over 7 nights in ARI) = 91 people.

- **Of these** 423 (50.2%) were from Aberdeen City, 217 (25.8%) from Aberdeenshire and 117 (13.9%) from Moray. The remaining 85 were from elsewhere in Scotland.

[2] A strategy for the Neurorehabilitation Centre and Care of Young Adults with Acquired brain injury in Greater Glasgow – T.M. McMillan, October 2003

4. Service User Consultation and Audit

Information to inform this strategy was obtained from the following:

- Brain injury Seminar involving people with acquired brain injury, their carers and staff working with people with acquired brain injury (November 2008).

- Survey distributed to patients, families and professionals working in acquired brain injury asking opinion on current services and views on gaps in service *(appendix c).*

- Interview with clients on the Momentum, Pathways return to work programme in about their experience of services and how they thought this could be improved. (September 2010).

- Feedback from a patient representative who is a member of the committee of Aberdeen city joint futures acquired brain injury group.

- A local audit of the services to patients with Acquired brain injury at various stages in the patient pathway was conducted to examine current working practises and potential alternative ways of working (2006).

What we are doing well:

Positive comments were made during consultation about several services, most notably about **Momentum (including Transitions).** There were many comments from patients and carers about the support received from Transitions service. Professionals have also noted the benefits for patients from the social activities, information, training and support provided by this service.

Improved Communication. Consultation revealed a perceived improvement in communication between services and patients and carers felt that NHSG and the council service were more aware of the needs of people with acquired brain injury. It was recognised however that there is still progress to be made in this area.

What is still needed? (not in order of priority):

Carer Support. There is a lack of services providing specific support for carers including access to emotional support and support for new carers.

Community rehabilitation services. Improvement in residential rehabilitation services have highlighted the gaps in community rehabilitation services e.g. following discharge, patients do not receive the support and rehabilitation opportunities consistent with the level of specialist care offered at Craig court. This in some cases can be detrimental to the level of independence and recovery achieved by the patient (and in the long term cost to services). A community team providing specialist rehabilitation, support, information and training for people with acquired brain injury, their carers and other professionals working with people with acquired brain injury remains a priority.

Respite. A need for appropriate respite which meets the needs of people with acquired brain injury, particularly younger people. Family members are reluctant to use respite if

they feel the experience will not benefit the person with acquired brain injury which causes more family stress and increases the likelihood of breakdown.

Housing. More appropriate sheltered housing and housing for people with high level of care needs was raised especially for young people with acquired brain injury, people with behavioural difficulties and people with severe cognitive impairment.

Communication. Despite improvements in this area, consultation revealed examples of poor communication and lack of co-ordination of services.

Support throughout the lifespan. Acquired brain injury is a life long condition. There is a need for people to be able to access services as their needs change at different stages in their life. A need for more psychological support, more opportunity to meet with peers and appropriate day care and social activities were highlighted.

Information. The need for more information about the services that are available in community settings was highlighted.

Training. There are no formal training courses available for staff working with people with acquired brain injury.

5. Standards and Guidelines

The National Service Framework for Long term conditions (2005) is a ten year programme for change seeks to transform health and social care provision for people with long term conditions and includes acquired brain injury. It specified 11 Quality Requirements (QR). QR5 Community rehabilitation and support states the following evidence based markers:

- There is improved access to community rehabilitation
- Local multidisciplinary rehabilitation and support are provided in the community by professionals with the right skills and experience
- Providers of community rehabilitation and support services support people and their family members or carers

Review of the **Scottish Acquired brain injury Network Standards for Traumatic Acquired brain injury in Adults standard 1** in September 2010 (*appendix d and e)* revealed that the following standards are **not** being met by NHS Grampian:

- There is a named lead clinician or senior manager with responsibility for the planning and review of traumatic acquired brain injury services, who is a member of, or reports to the NHS Board (1.1)
- There is a of range of public & patient/carer involvement in the planning of TBI services (1.5)
- Education and training needs of staff providing services to people with TBI are identified and are included in their individual development plans (1.7)

Scottish Needs Assessment Programme (SNAP) report indicated that services for people with acquired brain injury in Scotland were inadequate and made a number of recommendations including:

- greater involvement of users and carers in the integration of services.
- agreed care pathways for professional and carers.
- agreed standards of care to complement the care pathways.
- improved access to information for professionals and service-users.
- improved collection of data to inform the planning of services.

British Society for Rehabilitation Medicine Standards for rehabilitation services recommend that people living in the community with long-term conditions should have timely and on-going access to a named individual or team with experience in the management of their condition.

6. Current service provision

Services Specialising in Acquired Brain Injury.

- **Momentum** Acquired brain injury Vocational Centre offers vocational assessment, training, and development programmes for people with acquired brain injury.

- The **BIG-Group** enables carers to share experiences and helps those with acquired brain injury to be less socially isolated via a programme of meetings, events and activities.

- **Craig Court** offers residential rehabilitation for people with acquired brain injury.

- **Transitions** deliver an outreach programme which offers support to people with an acquired brain injury and their families throughout Grampian.

NHS Grampian.

- **The Neurosurgery and Neurology Ward, Aberdeen Royal Infirmary**, offers acute care and clinical assessment by a multi-disciplinary team

- **Neuro Rehabilitation Unit, Woodend Hospital**, offers specialist post acute rehabilitation for a number of conditions, including acquired brain injury.

- **Royal Cornhill Hospital** offers long term care for individuals with mental health problems, including those who have an acquired brain injury.

- **Deeside Neurological Support Service** offers assessment, treatment, support and education for people in the Deeside Community with any neurological condition including traumatic brain injury.

- **Horizons Rehabilitation Centre** (NHS G and city council) offers rehabilitation programmes for patients across Grampian with a number of conditions, including traumatic acquired brain injury.

Aberdeen City, Moray and Aberdeenshire Councils

- **Social Work/ Care Management** services are offered, to develop packages of care in co-operation with Primary Health Care.

- The **Moray Resource Centre** offers a specialised service for individuals with a physical and sensory disability. The service aims to help individuals adjust to change, learn new skills, gain self confidence, return to education/work and participate in the development of the service.

- **Welfare rights services** offer free, impartial and independent advice on social security benefits, revenue and customs and tax credits benefits.

- **Housing services** address the housing needs of people with acquired brain injury and their families

7. Priority Areas

Considering local consultation and national acquired brain injury standards, the following two main priorities were identified.

Clinical Leadership
The appointment of a lead clinician or senior manager with responsibility for the planning and review of acquired brain injury services. This is an essential criteria of the Traumatic Acquired brain injury National standards *(appendix d).*

Development of Community Acquired brain injury Team including continued funding for Transitions. The need for a community acquired brain injury team was identified in 2004 and remains a significant need in 2011. For a description of the role of this team see *appendix f.*

8. Actions

1. **Lead clinician/ manager for Brain Injury.** Identify and appoint a lead clinician and/ or senior manager with responsibility for the planning and review of traumatic brain injury services.

2. **Acquired brain injury Community Team**
   a. confirm long term support for Transitions acquired brain injury service.
   b. Support the existing local managed care networks to continue to develop their role including strengthening the link between local acquired d brain injury managed care networks and Grampian managed care network.
   c. Increase awareness of local MCNs among professionals working with people with acquired brain injury.

3. **Carer Support.** Improve opportunities for support and access to support for carers of people with acquired brain injury.

4. **Service User Involvement.** Increase invites to Grampian MCN. Hold one event every two years for user consultation. Yearly visit to Momentum by reps from Grampian BI MCN.

5. **Employment.** Contribute to maximising the number of people with acquired brain injury in employment through supporting Momentum and employing the employability strategy.

6. **Respite/ Short breaks.** Increase range of opportunities for respite and facilitate access to these services for people with acquired brain injury and their families.

7. **Support for people with BI across the life span.** Promote peer support activities within council and NHSG

8. **Housing.** Liaise with housing to inform on the needs of people with acquired brain injury.

9. **Training.** Compile list of training currently running in Grampian and eligibility for access. Increase awareness of the Scottish Acquired Brain Injury network online training resource. Identify gaps in staff individual development plans on acquired brain injury education.

10. **Acquired brain injury Standards.** Review Scottish Acquired brain injury Network / Quality Improvement Scotland standards, identify those not met and form a plan to work towards meeting standards.

11. **Increase links with Scottish Acquired Brain Injury Network (SABIN).** Invite Manager of MCN to Grampian MCN meeting once a year.

12. **Improve demographic and outcome data on people with brain injury**
    a. Attempt to gain recent data on numbers of acquired brain injuries occurring in Grampian each year.
    b. Collate demographic and outcome data from services working with people with brain injury (including Craig court, neuro-rehabilitation ward, Transitions and Horizons)
    c. Encourage local MCNs to keep records of numbers of patients discussed/ referred and share this data with the Grampian Brain Injury MCN.

APPENDIX A

Contributors to the Grampian Brain Injury Strategy 2011-2016

Dr Maggie Whyte	Consultant Clinical Neuropsychologist, NHS Grampian
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Rev James Falconer	Chaplin, NHS Grampian
Rhona Davidson	Senior Physiotherapist, NHS Grampian
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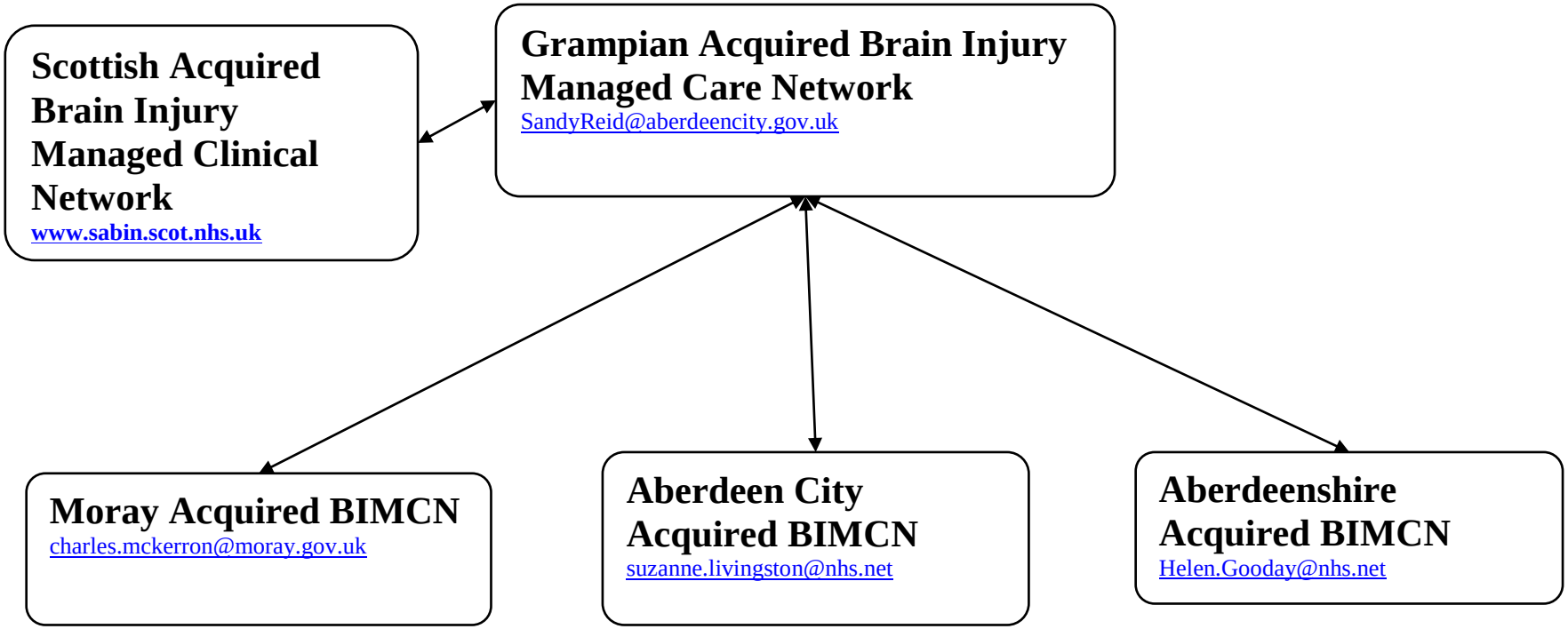
Claire Fitzsimmons	Occupational Therapist, NHS Grampian
Michelle Coulson	Service User
Sandy Reid	Programme Development Manager, Aberdeen City Council/ Aberdeen CHP
Sheena Swinhoe	Strategic Development Officer (Community Care), Aberdeenshire Council
Rieta Vilar	Joint Future Planning Manager, Aberdeenshire CHP
Charles McKerron	Service Manager, Moray Council
Dorothy Strachan	Clinical Services Manager, Momentum Scotland
Rachel McPherson	Acquired Brain Injury Outreach Worker, Transitions

APPENDIX B Overview of Brain Injury MCN development in Grampian

NHS Grampian + Voluntary Organisations (Inc. Transitions/ Momentum) + Aberdeenshire/ Moray/ Aberdeen City Councils



APPENDIX C

Grampian Brain Injury Strategy 2011-2016 Questionnaire Results

27 responses were received from people with brain injury, their carers and families (14) and professionals working with people with brain injury (13). Responses were received from people in Aberdeen city, Aberdeenshire and Moray.

Which aspects of services you received did you find helpful?

Positive comments were made about experience of care in hospital, physiotherapy in hospital, momentum, Transitions, acute care, neuropsychology, occupational therapy and Craig court.

Examples of comments
"Transitions have been excellent"
"one to one contact with Rachel from Transitions" (was most helpful)
"Momentum provided a safe environment to learn and talk to others who had had a brain injury"

What do you think are the main gaps in service in Grampian?

The following aspects of service received comment from more than 4 people:

- Lack of information about services that are there to help
- No follow up 'check' e.g. to see how people are 6 months or 1 year after injury
- Need for services to respond to changes across the lifespan/ provided support at different times in life, especially for those living without care.
- A need for the full development of a community brain injury team (as per original strategy).
- Need for more support for carers especially new carers including emotional support, someone to talks to.
- Need for suitable respite care
- Lack of co-ordination of service provision e.g. have to deal with several people and repeat self lots.
- Need for improved training for staff in the community
- Lack of appropriate sheltered/ supported housing, especially for young people
- Need for appropriate social activities, day care, and a social hub to meet with others.

The following comments were made by one of more people:

- Lack of flexible support i.e. not able to easily drop in and out of services
- Services need to promote independence rather than dependence
- Large gaps in community rehabilitation and lack of co-ordinated care
- Lack of communication between professionals, lack of continuity of care on discharge
- More time needed with neuropsychology
- Improved GP knowledge of brain injury needed
- Lack of services on discharge from hospital

- Need for service for people who are not able to return to work i.e. not suitable for momentum.
- Need for anger management sessions
- Waiting lists for services are too long
- Help is too city based
- Need for more support workers (more hours to be available through social care)
- Need for appropriate services for people with challenging behaviour
- More emotional support for people with brain injury and mental health problems
- Need to appoint a clinical lead
- More transition workers needed
- Social rehabilitation facilities are needed
- Need for easier access to community services including employment, sport and leisure
- Need for easier access to specialist therapies in the community
- Need for a 'drop-in' centre providing support/ information/groups/ clubs/ therapies

Examples of comments

"There have been lots of good development in recent years however further funding is now needed in order to develop community services"

"Currently the foundations formed by Maidencraig Rehabilitation Unit and Craig Court are not being strengthened or built upon effectively when patients leave hospital."

"There are very limited services in the community and a lack of brain injury awareness"

APPENDIX D

The Scottish Acquired Brain Injury Network. National standards for Traumatic Acquired brain injury is available at www.sabin.scot.nhs.uk/files/standards.pdf

Standard 1: Organisation of care for people with traumatic brain injury			
Standard Statement 1 In each NHS Board the needs of adults with traumatic brain injury (TBI) have been clearly identified with planning and service provision in place.			
Rationale: Public involvement, inter-agency co-operation and joint working are required to plan, design and deliver high quality, integrated services.			
Essential Criteria		**Examples of evidence**	**Evidence currently available**
1.1	There is a named lead clinician or senior manager with responsibility for the planning and review of traumatic brain injury services, who is a member of, or reports to the NHS Board **Currently a Clinical Lead for brain injury services within NHS Grampian is not in post.** **GAP: Part of this is being attempted by clinicians at a cost to their service and results in an inadequate outcome. A dedicated session by a clinician for this work would make a huge difference to the planning and co-ordination of services for people with BI. This has already been identified as the main priority (in the draft for the 2010-2016 BI strategy).**	Recognised lead person for TBI. Remit in job description. Reporting arrangement.	
1.2	The NHS Board should be able to demonstrate that there is a current, clear strategic plan for TBI across the continuum in partnership with Local Authority and Voluntary agencies. **There is a BI strategy for 2004-2010 (however the main aim of this has not been met). A review of the strategy is being developed and is expected in March 2011.**	Joint strategic plan for TBI which is current, documented, dated and has timescales.	**Grampian Brain Injury strategy 2004-2010.** **Minutes from Grampian managed care network Sept '10 detailing discussions on**
1.3	The NHS Board should collect and collate data on activity at all points in the patient pathway and be able to demonstrate how this data has been used to plan and co-ordinate service provision.	Activity data available and referred to in the strategic or service plan.	**Monthly statistics for Craig Court and in-patient wards**
1.4	There are formal partnerships established between NHS Boards, Local Authorities and other providers of services to people with TBI to determine strategy and commission services.	Interagency group • remit, • minutes, • implementation plan.	**Overview of Brain Injury MCN development in Grampian** **Briefing paper on Grampian MCN for Brain Injury**

	Grampian Managed Care Network for Brain Injury established 2008.		
1.5	There is a of range of public & patient/carer involvement in the planning of TBI services. **Grampian Brain Injury Seminar (Nov 2008) included service users in consultation.** **Service user representation on Aberdeen City Joint Futures Brain Injury Group** **Service users have been consulted about the Grampian Strategy for BI 2011 -2016 through interview and questionnaire (see minutes of Joint Futures Group Sept '10)** **GAP: More needs to be done in this area and is a priority recognised by the Grampian Strategy for BI 2011-2016.**	Reports from public/ patient involvement events, consultation.	**Grampian Brain Injury Seminar Report Nov 2008** **Minutes from Aberdeen City Joint Futures Meeting Sept '10**
1.6	All NHS boards will have a named lead consultant who is responsible for ensuring that patients are assessed for and, if appropriate, offered a rehabilitation programme. **Helen Goody is the named Clinical Lead who is responsible for ensuring patients are assessed for rehabilitation programmes.**		
1.7	Education and training needs of staff providing services to people with TBI are identified and are included in their individual development plans **GAP: There is a lack of consistency in training across service providers. No training programmes exist for community staff. There needs to be more co-ordination of training with a training co-ordinator in place. Training is often arranged by clinicians when a need is identified for a particular patient (at a cost to services and other patients).**	Training needs assessments, brain injury awareness and training programmes, induction programmes.	**Learning plan** **Staff Annual Professional Development Plan** **Staff induction training programme 1** **Staff induction training programme2**

Appendix f

Community Brain Injury Team

Support and information for people with brain injury throughout the lifespan.

- Access to support or advice without waiting list
- Check in service (contact on yearly basis from team).

Support for family and carers:

- access to information/ support from admission through discharge and in community
- Facilitate links with services in social work and voluntary sector
- Education and advice

Treatment:

- Goal targeted treatment aimed at reducing disability and maximising independence. To include: cognitive rehabilitation, daily living skills teaching, social rehabilitation.
- Treatment for psychological disorders or adjustment reaction as a result of brain injury e.g. depression, anxiety, anger
- Treatment for behavioural disturbance following brain injury.
- Social rehabilitation – goal directed treatment of social disability including experiential learning and practise of social skills.
- Family therapy

Communication and Co-ordination of services:

- Facilitating links with and between services supporting or providing a service to people with brain injury (including services for people with multiple and complex problems e.g. alcohol, forensic, mental health)
- Co-ordinating care between services and sharing information (following consent) between agencies on behalf of the patient.

Training

- Co-ordination and implementation of training programmes for support staff, nursing/ residential home staff and community staff (including care managers, OTs, physios).
- Education and training programmes for carers.

Core members of the team would include a Clinical Neuropsychologist, Occupational Therapist, Physiotherapist and therapy assistant and sessions from a community nurse and Clinical Psychologist