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## **ACQUIRED BRAIN INJURY REVIEW 2009**

Acquired Brain Injury is sadly common and often leads to long-term illness and disability. Frequently the most difficult challenges for patients and their families is in addressing the neuropsychological and neuropsychiatric sequelae, including cognitive impairment, organic personality change and challenging behaviours.

The incidence of serious mental illness including depression is also high in this population. Those who have suffered a brain haemorrhage, brain tumour, or hypoxic brain injury and those affected by some neurological conditions including Huntington's disease may experience similar problems.

There have been welcome developments in the provision of treatment for people following acquired brain injury. The opening of the Regional Acquired Brain Injury Unit at Musgrave Park Hospital and the development of community brain injury rehabilitation teams represent significant advances. As clearly identified in the Ministerial review there are still critical gaps in service provision to be addressed.

The needs of those who have suffered significant brain injury can be complex and long term and can emerge at various points in the course of recovery. They cross traditional service boundaries. There are often social, medical and psychological needs to be met. It is encouraging therefore that the Review and Draft Action Plan envisages a networked and integrated approach. This initiative must include appropriate resources to address mental health needs, including cognitive and neurobehavioural problems.

Planning and delivery of effective services requires knowledge of the epidemiology of the conditions.

It is important that those with mental health needs are able to access appropriate services in a timely manner.

The needs for residential support vary from person to person and can change with time. For a number of people this need will be on-going. The environments in which care is provided must meet standards for safety, dignity, and promote well-being.

## **COMMISSIONING**

The College welcomes the concept of a regionally managed clinical network for acquired traumatic brain injury, underpinned by strategic direction and adequate resource.

The planning process should take into consideration the similarities in needs of people with other neurological conditions such as stroke and the rehabilitation needs of those following surgery for conditions such as brain tumours.

There could be gains in terms of efficiency if this group liaised with those planning for the provision of services for other long-term neurological conditions as often these skills and resources required will be similar and there could be efficiencies in provision of training and resources.

The needs assessment identified specifically with regard to older people and children with acquired brain injury should also include an assessment of need for support for adults with brain injury who may be invisible to existing brain injury services through having been placed in facilities not designed to meet their needs, for example nursing homes and psychiatric hospitals. Consideration should be given to carrying out an epidemiological assessment.

We welcome the intent to provide treatment for individuals as close to home as possible. For the benefit of those whose opportunities are severely limited by the neuropsychiatric sequelae of their brain injury this will involve provision of a tiered model of care with in-patient challenging behaviour facilities, step down intensively supported facilities, specialist supported facilities and residential facilities in the community along with input from community brain injury teams. In line with a model of providing the right service in the right place this should lead to overall efficiency savings by facilitating the earlier discharge of people who are inappropriately residing in hospitals and other care facilities, and the return home of those whose treatment is currently being purchased from services in Great Britain.

We welcome the emphasis on needs of the family and carers in service provision.

## **IN-PATIENT AND OUT-PATIENT SERVICES**

We welcome the prominence given to the needs of children who have acquired brain injury. In the provision of services for children and adolescents with brain injury, as with services for adults, there is a need for access for tiered services with appropriate in-patient and residential places and support on discharge. The direct and indirect effects of brain injury can have an adverse impact on emotional development, particularly through adolescence and the ability to mature and develop in appropriate social and learning environments. It is important that children and adolescents have access to therapists with expertise in the provision of treatment for this age group.

There is a need to develop a body of expertise locally and nationally with regard to the treatment of the consequences of acquired brain injury. There is a need for research nationally into the effectiveness of treatments particularly in the management of neuropsychiatric and neurobehavioural sequelae of brain injury. Extending the knowledge base will require collaboration not just regionally but nationally.

There is a need for education and dissemination of information regarding best practice in brain injury rehabilitation. The development of a core regional multi-professional team with appropriate training and expertise should provide a resource regionally. As envisaged in the Bamford Review model it should be possible for staff to work across team boundaries providing expert input to support and train staff in local teams, thus enabling a high quality service to be provided and teams to develop. The need for such training applies not just in physical rehabilitation but also in the neurobehavioural and neuropsychiatric aspects of care. The Regional challenging behaviour unit, currently based at Maine Ward, Knockbracken Healthcare Park, should also be developed as part of this resource for training, education and research.

The review is correct in recognising the need for appropriate environments within acute hospitals for the provision of care for those with brain injury. Often individuals require a quiet and controlled environment. There is a risk that those with cognitive impairment may wander from open acute wards. This type of provision can also be required for those who have cognitive impairment and require admission to general hospitals. The need is not specific to those who have suffered an acquired brain injury. Access to psychiatric liaison services in such circumstances is also of importance

The recruitment and training of expert nurses linked with a brain injury specialist service has merit, not only in physical rehabilitation, but also in the area of neurobehavioural rehabilitation. The role of an expert brain injury rehabilitation nurse in a neurobehavioural service could include the coordination of care through the system from the process of admission to the neurobehavioural ward on through to the establishment of care in the community. Their role could help optimise the efficiency of service provision and identification of appropriate facilities for care and support.

The review recommendations mention the utilisation of Spruce House and its development as a sub-regional in-patient and out-patient facility. It would be important that as well as the involvement of a consultant in rehabilitation medicine provision is made for neuropsychiatric input.

The College welcomes the recognition in the report for the development of alternative accommodation for the regional in-patient service for people with challenging behaviour. It is not acceptable that there is currently no facility for the admission of women, while it is clear that the current environment is not fit for purpose in 2009. It is imperative that the development of in-patient and residential services are planned as part of an overall regional service. The issue is not just the provision of a challenging behaviour ward with an improved environment - vital though this is - but rather the provision of comprehensive and high quality modern service adequately resourced with a multidisciplinary staff team including neuropsychiatry, neuropsychology, nursing and occupational therapy, speech and language therapy and physiotherapy.

In order to deliver an efficient and effective service there must be strong relationships with other services and especially with the Regional Acquired Brain Injury Unit at Musgrave Park Hospital. In order that appropriate support is available for patients who very often have complex physical care and rehabilitation needs as well as severe neuropsychiatric problems it would be most appropriate to locate the in-patient unit in close, if not indeed intimate proximity to RABIU so that the neurological rehabilitation service could facilitate efficient patterns of working and sharing of expertise. Placing psychiatric and medical inpatients on the same site is of course in keeping with all modern thinking and should contribute to destigmatising the neuropsychiatric patients.

The development of this service will require the resourcing of an expert multidisciplinary team with staffing levels across a range of disciplines in accordance with those in bench mark services elsewhere, for example in Edinburgh and London.

There is a need for intensively supported step down residential accommodation to allow people to capitalise on the gains made in rehabilitation. For some patients there will be a need for longer term intensive supported specialist places. The absence of such step down options would lead to a situation where people are trapped - as at present - in the challenging behaviour unit.

Highly supported community placements are also required. Service provision must allow individuals and their families to capitalise on Recovery, which is now a key ethos in term conditions; without appropriate provision it is likely that gains in rehabilitation will all too often not be maintained.

The report identifies the need for enhancement of neuropsychiatric provision and support across the ATBI network. As with the identified need for additional consultant input in rehabilitation medicine, there should be provision for an additional consultant post in neuropsychiatry to enhance and support the service of the ATBI network.

The establishment of community brain injury teams across the region has been a significant development. The report identifies the need to secure equity of access to services provided by such teams and it is important that the staff profiles of teams are enhanced to ensure access to the range of specialist input required including speech and language therapy, occupational therapy, physiotherapy, nursing and clinical psychology. The community rehabilitation teams currently sit within physical disability services. However there is a clear need for close working between the community injury teams and local mental health teams. There is often co-morbidity as patients who have sustained a brain injury frequently have coexisting mental health and neuropsychological issues. Sharing of expertise between teams is essential.

It is imperative that people with co-existent neurological conditions are able to access treatment for mental health issues and that mental health services are supported in managing complex cases by brain injury rehabilitation teams. The concept of networked care with services being provided in accordance with the needs of the individual must be adhered to. If such integrated service planning does not take place then there is a risk that patients will fall between programmes of care.

The College endorses the recommendation that age appropriate respite services be developed for people with brain injury living with carers. This need applies across the range of age groups. Such services should be sufficiently flexible to address the need for brief and longer terms of respite care. The expertise and experience of carers should be given due consideration in the planning and provision of such respite for individuals.

## **VOLUNTARY SECTOR**

Services for vocational rehabilitation and social reintegration are clearly important and should be maintained. In the management of such services it must be recognised that for some individuals the service will provide a stepping stone to more independent activity, but for others there will be the opportunity for longer term supported structured activity.

Because of the nature of brain injury the capacity of patients to engage in certain activities can be limited. In the planning and provision of services there is a need for a range of options from low key highly structured placements through to more active schemes. Our services must be patient-centred and need to be able to respond to the differing needs our patients have at different times.

It is important that the range of services developed and purchased from non statutory providers complements the overall regional service provision. Service planners, commissioners and Health and Social Care Trusts must therefore work closely with key non-statutory/voluntary sector providers in the planning, provision and delivery of specialist services. There should be an opportunity for Health and Social Care Trust staff to work alongside non-statutory service providers in the provision of care, particularly for those with complex needs.

The recommendation relating to the forum for service users and carers is applicable to the whole range of services and for acquired traumatic brain injury. The extent of the development of user and carer groups across the region varies. The development of a Regional Forum encompassing service users, carers and professionals should be facilitated. The Northern Ireland Traumatic Brain Injury Forum (NITBIF) has to date engaged in useful projects including a workshop on services for children with acquired brain injury leading to recommendations for service development in key areas. Such work should in future be facilitated. The development of enhanced links between the user and carer forum regionally, and established national groups such as Headway and the Child Brain Injury Trust (CBIT) which already exist should be facilitated and supported. That support could be provided for the service users' and carers' forum to work on particular projects that would help inform service planning and development groups. A properly constituted service user and carer forum could also be an important educational resource for those providing services.

### **STAFFING PROFILE**

It would be informative for planners if the staffing profiles locally could be shown alongside staffing profiles for benchmarked units elsewhere such as The Robert Fergusson In-patient Neurobehavioural Rehabilitation Unit in Edinburgh and The Lishman Unit at the Maudsley Hospital in London. A look at other services makes clear the gaps in the staff complement in the local neurobehavioural unit (Maine Ward in Knockbracken Healthcare Park) compared with the services elsewhere. There is a need for specialist speech and language therapy provision, specialist physiotherapy, an increased level of occupational therapy and the development of a team of nursing staff who have access to appropriate training in brain injury rehabilitation.

The neuropsychiatry consultant provision for Maine listed as 0.3 in the table is currently resourced at a level of 2 half day sessions per week. To facilitate development of an appropriate in-patient neurobehavioural service and provide enhanced input to the Regional Acquired Brain Injury Unit would require an increase in neuropsychiatry sessional input for in-patient services. The report elsewhere identifies the need for an enhancement in the level of neuropsychiatry provision and support across the ATBI Network and to this end there is a requirement for an additional consultant post in neuropsychiatry.

### **LEARNING DISABILITY**

The Learning Disability Faculty of the College welcomes the document, as this specialty cares for children with head injury, some of whom have entered learning disability services primarily because of the absence of a more suitable service. It is important that this group of individuals is not ignored.

## **NEUROPSYCHIATRY**

The College has consulted with Dr Peter Trimble, Consultant Neuropsychiatrist, in the preparation of this response.

## **CONCLUSION**

The College welcomes the opportunity that the review commissioned by the Minister has given to identify areas where there is great need for service development. Psychiatrists, along with other professional colleagues, have been all too well aware that through no fault of their own they have been unable to deliver the kind of service that they would wish to be available for patients with acquired traumatic brain injury. This review and provides an opportunity for the development of well planned and co-ordinated person-centered services. There have already been significant improvements in brain injury services with the opening of the Regional Acquired Brain Injury Unit. It is clear from the review that it is not just the individual components but a comprehensive networked service that is required. It is imperative that funding is made available to enable the appropriate recommendations to be implemented.

The College looks forward to continue working with the Department to expedite the development of a first class service for our patients.

A handwritten signature in cursive script that reads "Philip McGarry". The signature is written in black ink on a white background.

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The Royal College of Psychiatrists  
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8<sup>th</sup> June 2009