A Comprehensive Service System for Queenslanders with Brain Injury

Positioning Paper

Quarterly Brain Injury Services Meeting (QBISM) Group

August 2013

Final
EXECUTIVE SUMMARY

Almost one in 45 Australians is affected by ABI related disability. Queensland has the highest national rate of ABI compared to all other states and territories. In 2003, there were 82,600 people living with ABI related disability in Queensland. It is anticipated that this number will grow as more people survive brain injuries sustained through accidents, stroke, assaults and a range of other causes each year. In 2004/05 alone, there were over 8300 hospital admissions related to ABI in Queensland. Despite these statistics, Queensland lacks the range of services and supports available to people with ABI in other Australian states. Major obstacles to optimising positive outcomes for people who sustain an ABI include limitations on rehabilitation beds, a paucity of appropriate accommodation options, difficulties and delays accessing care and support funding, and restricted access to community rehabilitation services and case management support. All these obstacles contribute to the inherent cost inefficiencies of the current service system.

People with ABI frequently have complex disabilities and diverse rehabilitation and care and support needs. They often require services from a range of different government departments, levels of government, and the private and non-government sectors to support their transition through hospital based services and return to community living. Coordinated cross-government and interagency planning is pivotal to ensure seamless service delivery that promotes optimal functional recovery and active participation in social and economic life. However, people with brain injury and their families experience the Queensland service system as inconsistent and difficult to understand. They report significant barriers to securing adequate information, service access and support. In the face of these difficulties, young people with ABI and high care needs are at risk of residential aged care placement or extended stays in health care facilities. Others who return to the community experience high rates of anxiety, depression and suicide risk. Their families often experience significant levels of distress.

It is anticipated that implementation of the National Disability Insurance Scheme (NDIS) from July 2016 will help to improve the supports available to some people with ABI and their families in Queensland. However the NDIS will not fund services ‘more appropriately funded’ through other systems, including rehabilitation and post acute care, housing, employment, education and training services. Collaborative state-wide service planning is therefore required to ensure an integrated systemic response to the needs of Queenslanders with ABI and their families. This position paper calls for the establishment of a state-wide strategic planning body and the development of a state-wide ABI service plan to ensure integrated service planning, improve post injury pathways and enhance the comprehensiveness and cost efficacy of the current service system.
Key Recommendations

1. Collaborative state-wide service planning to improve the pathways and outcomes of people with brain injuries and their families in Queensland and the cost efficiency of the current service system
2. Increased government investment in developing a range of accommodation and support options for adults with brain injury residing in metropolitan, regional and rural areas of the state
3. Development of specialist community rehabilitation and case management services, and adequate supports for participation throughout the state to promote the optimal health and wellbeing of both adults with brain injury and their family members
4. Increased government investment in building specialist service capacity in regional, rural and remote communities
5. The systematic collection and analysis of data regarding post injury pathways, service utilisation costs and outcomes after injury to inform the design of an evidence based, responsive, cost-efficient state-wide service system.

SCOPE

This position paper was developed as a collaborative project of the Quarterly Brain Injury Services Meeting (QBISM) group through the concerted efforts of Rosamund Harrington (University of Queensland), Associate Professor Heidi Muenchberger (Griffith University), Dr Ron Hazelton (Director BIRU), Erin Griffin (Jacana ABI Service), Sarah Raffell (Casuarina Rehabilitation Centre), Brooke Kooymans (Rehability), Clare Humphries and Dr Clare Townsend (Synapse). Informed principally by the QBISM, the purpose of this position paper is to report on the current context of brain injury rehabilitation in Queensland, service gaps in adult brain injury rehabilitation and community support from the perspectives of health and disability practitioners, and to consider possible solutions for improved state-wide practice. The paper integrates the results of recent ABI research projects involving adults with ABI, their families and specialist service providers in Queensland; previous reviews of the Queensland ABI service system; and group consultations involving STEPS program leaders coordinated by ABIOS in 2011, and attendees at the "ABI Rural & Remote Challenge Forum" coordinated by Synapse and the ABI Learning Network Far North Queensland in 2010.

Membership of the QBISM group includes representatives from:

- The Princess Alexandra Hospital Brain Injury Rehabilitation Unit (BIRU)
- The Acquired Brain Injury Outreach Service (ABIOS)
- Casuarina Rehabilitation Centre
- Jacana Acquired Brain Injury Service
- The Royal Brisbane and Women’s Hospital Neurosurgical Unit
NATIONAL AND INTERNATIONAL POLICY CONTEXT

Current international and national disability policies and conventions highlight the need to develop systems and supports which enable the full inclusion and participation of people with a disability in the community.

UN Convention on the Rights of Persons with Disabilities: At an international level, Australia is signatory to the UN Convention on the Rights of Persons with Disabilities. This convention recognises the rights of people with disability to live in the community, to exercise choice over where and with whom they live, and to receive the support required to enable their inclusion in the community. Additionally, signatory nations agreed to organize, strengthen and extend comprehensive rehabilitation services and programs to ensure that rehabilitation begins at the earliest possible stage and that rehabilitation services are available as close as possible to peoples own communities, including rural areas.

To support achievement of these aims, the Australian Government has progressed the implementation of two National Disability and Injury Insurance schemes which will individually impact on disability support, and access to rehabilitation and lifestyle services for people with permanent acquired injury and illness. The two schemes are broadly outlined (as per the National Disability Insurance Scheme Act 2013 and Productivity Commission Disability Care and Support Report, 2011) below:
National Disability Insurance Scheme (NDIS): The NDIS, administered by Disability Care Australia, will provide lifetime care and support for people with permanent impairments who meet eligibility requirements, with the aim of assisting them 'to realise their potential for physical, social, emotional and intellectual development' and 'participate in social and economic life' (National Disability Insurance Scheme Act 2013, p. 6). Funding may be provided to individuals to allow for essential home modifications, aids and appliances, personal care, domestic assistance, community access, transport assistance, maintenance therapies, supports for employment, and local area coordination and development. The NDIS will not fund supports and services considered to be more appropriately funded through other service systems including health, housing, employment, education and training services.

National Injury Insurance Scheme (NIIS): This proposed scheme aims to harmonise existing accident and injury insurance arrangements across all Australian States and Territories by creating a federation of separate, state-based no fault catastrophic injury schemes. Under the Productivity Commission’s 2011 proposal, the NIIS scheme will provide no-fault lifetime care and support for all Australians acquiring new catastrophic injuries, providing a similar level of coverage to the ‘no fault’ motor accident insurance schemes currently operating in some Australian states and territories. In contrast to the NDIS, the proposed NIIS would fund all stages of an injured person’s rehabilitation trajectory, including access to hospital based services, such as specialist inpatient rehabilitation units. Injured persons who can establish negligence against another person would retain their right to sue for loss of income and other general damages (excluding lifetime care costs) under common law. The NIIS proposal recognises the importance of planned investment in building specialist service capacity and coordinated injury management at a state-level with the Productivity Commission reporting that:

‘the experience of jurisdictions with no-fault accident schemes has been that coordinating optimal transitions through the health system and the availability of high quality rehabilitation facilities enhances participant outcomes and reduces the lifetime cost of injury’ (p. 866).

Heads of Government Agreement between the Commonwealth and Queensland Governments on the National Disability Insurance Scheme:

In May 2013 the Queensland government signed an agreement to commence full transition to the NDIS from 1 July 2016. Under this agreement the Queensland government also agreed in principle with the NIIS minimum national benchmarks. From 1 July 2016 they will be responsible for 100 per cent of the cost of NDIS participants who are in the NDIS because they are not covered by an injury insurance scheme that meets minimum benchmarks for motor vehicle or workplace accidents. The feasibility of extending the existing at fault CTP scheme to provide ‘no fault’ coverage to adults catastrophically injured in motor vehicle accidents will also be investigated.
CURRENT CONTEXT OF ADULT BRAIN INJURY REHABILITATION IN QUEENSLAND

As illustrated in the figure below, Queensland has the highest national rate of ABI disability (82,600 cases reporting disability status after ABI compared to 77,800 in NSW, 73,800 in Vic, 31,000 in SA)\(^1\). However, it lacks the range of ABI-specific rehabilitation services available in other Australian states\(^2\).

Strengths and weaknesses are clearly evident in current Queensland brain injury rehabilitation:

**STRENGTHS of Queensland Brain Injury Rehabilitation**
- Acute medical care and emergency retrieval systems
- Rehabilitation workforce competency development
- Community resources – STEPS (ABIOS), University partnerships and place-based responses
- Research and development – CONROD, CARRS-Q
- Consumer resources – self-management skills development in chronic disease

**CHALLENGES of Queensland Brain Injury Rehabilitation**
- Lack of coordination of services to support transitions from hospital to home
- Inadequate residential/accommodation and support options following acute in-patient care
- Lack of specialist rehabilitation service availability
- Assessment and treatment of co-conditions and mental illness prevention
- Minimal data collection efforts – there exists no system for registering or monitoring the brain injury population in Queensland
- Absence of a cohesive state-wide organisational structure and clinical networks for brain injury rehabilitation.

*Source: AIHW, 2007*
Primary acute care settings in Queensland can deliver excellent emergency retrieval and acute medical care. However, there are notable gaps in the provision of brain injury rehabilitation services and coordinated service delivery following this acute phase. In 2006, development of ABI-specific rehabilitation services throughout the state was identified as one of the most pressing areas of need in the state trauma plan\textsuperscript{10}.

'\textit{Rehabilitation services for people with traumatic (and other acquired) brain injury are seriously reduced compared to other states and all districts and zones involved in this planning process identified brain injury rehabilitation as a significant need for their area.' (p.27)

**KEY RECOMMENDATIONS FOR IMPROVING ADULT BRAIN INJURY REHABILITATION IN QUEENSLAND**

Five key recommendations for improving adult brain injury rehabilitation in Queensland are outlined below. The recommendations were identified from QBISM participants over a two-stage Delphi process in 2011, ongoing consultations in 2012, and integration of feedback from the "ABI Rural & Remote Challenge Forum" coordinated by Synapse and the ABI Learning Network Far North Queensland in 2010.

**KEY RECOMMENDATION #1**

**Collaborative state-wide service planning is required to improve the pathways and outcomes of people with brain injuries and their families in Queensland and the cost efficiency of the current service system.**

This recommendation calls for the coordination of adult brain injury rehabilitation services across the rehabilitation trajectory (including intensive care, acute, sub-acute, and community settings). Although each rehabilitation setting can be considered a stand-alone area of practice, the transition between services is a critical component in ensuring continuance of rehabilitation progress and timely delivery of ongoing and new rehabilitation services. Supported transitions through the rehabilitation continuum are contingent on formalised processes for coordinating an individual’s post-acute care pathway, specialist service availability, and adequate funding for community based support. Integrating and streamlining referral and assessment processes for metropolitan based specialist rehabilitation services has been a focus of the QBISM group. However, a state-wide approach to service coordination and planning is required.

Adults with ABI frequently require support from multiple government and non-government agencies to successfully support their transition to community based living and meet their ongoing care and support needs. Over the past decade, Queensland based research projects have consistently identified
systemic barriers to service access and coordinated service delivery as a key area of concern for adults with ABI, their family members and service providers\textsuperscript{3,11,12,13,14}. Persistent difficulties obtaining suitable housing and community based support impede timely transitions through specialist rehabilitation services, compounding issues of ‘bed block’ in existing rehabilitation and acute care units, and limiting opportunities for early intervention. To address this issue, QBISM members identified the need for cross government collaboration as a number one priority for meeting the needs of adults living with ABI and their families in Queensland.

Difficulties negotiating access to funding in particular, and support from a variety of different government agencies, presents a challenge to both service providers involved in discharge planning and adults with brain injury and their families. Whole-of-government funding programs have been developed to integrate and streamline access to community based support and health care services for adults with other lifelong health conditions in Queensland, including the Spinal Cord Injuries Response and the mental health Housing and Support Program. However, no such program is currently available to adults with ABI. Subsequently, they may face prolonged hospital inpatient or residential care admissions. In the case of adults with ABI and high care needs, discharge from public hospital acute care units can be delayed up to 18 months and in some cases indefinitely, due to difficulties accessing care and support funding, and suitable housing.

Prolonged admissions to acute hospital units represent a significant cost to the public health care system. Additionally, issues of bed-block in specialist rehabilitation units can delay rehabilitation access and compound behavioural issues which adversely affect an individual’s potential to benefit from specialist services once available. For families, difficulties accessing required services, and limited support during the period of transition from hospital to home, have been found to contribute to high levels of carer strain\textsuperscript{3}.

Current data suggests that extended health care stays for people with ABI are on the rise, with the number of BIRU maintenance admissions increasing from 1 in 2011/12 to 7 in 2012/13. The costs of failing to support timely transitions through the current rehabilitation continuum are clearly illustrated in the three case studies presented in Table 1 below. Case study 1 reflects the costs associated with significant delays securing community living options for non-compensable adults with high care needs exiting rehabilitation units. In this case, the cost of remaining in an inpatient rehabilitation unit for over 400 days while awaiting a community care package was estimated to be over $700 per day more expensive than supported accommodation in the community. Case study 2 illustrates the reduced cost to the public health care system where streamlined transitions to the community are supported through access to compensation. Where compensation is unavailable, there are few alternatives to extended stays in health care facilities, as illustrated in Case study 3 involving a
young adult who continues to await alternative accommodation 6 years after an application for disability services funding.

**TABLE 1: Estimated costs of delayed transitions through the rehabilitation continuum**

<table>
<thead>
<tr>
<th>Phase of care</th>
<th>Case study 1 Non-compensable client severe head injury</th>
<th>Case study 2 Compensable client severe complex head injury</th>
<th>Case study 3 Non-compensable severe complex head injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute inpatient admission</td>
<td>Length of stay 34 days @ $1200 per day $40 800</td>
<td>266 days @ $1200 per day $319 200</td>
<td>724 days</td>
</tr>
<tr>
<td></td>
<td>Delay to next phase of care 5 days</td>
<td>169 days</td>
<td>496 days</td>
</tr>
<tr>
<td>Sub-acute inpatient rehabilitation</td>
<td>Length of stay 694 days @ $1200 per day $832 800</td>
<td>241 days @ $1200 per day $289 200</td>
<td>217 days inpatient rehab 7320 days slow-to-recover rehab unit</td>
</tr>
<tr>
<td></td>
<td>Delay to next phase of care 412 days</td>
<td>Nil –funded by Workcover</td>
<td>2130 days</td>
</tr>
<tr>
<td>Community based accommodation and rehabilitation</td>
<td>Period of rehabilitation N/A - awaiting supported accommodation</td>
<td>83 weeks (ongoing)</td>
<td>N/A - awaiting supported accommodation</td>
</tr>
<tr>
<td></td>
<td>Frequency of visit</td>
<td>Ongoing case management</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>6-7 sessions per week community based therapy @ $158 per hour</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>24/7 in-home care program - Approx $5200 per week</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Estimated costs related to delay in transition to the community $325 000 over 412 days</td>
<td>Nil</td>
<td>$195 000 - $335 000 over 6 years</td>
</tr>
</tbody>
</table>

*Cost estimates presented are calculated on the basis of current bed day costs for illustrative purposes only

*Estimated cost reflects difference between sub-acute bed cost and average cost of supported accommodation in the community as detailed in Appendix 1

The cost effectiveness of supporting adults with ABI and high care needs to transition to the community is clearly documented. Evaluation of the Victorian ABI: Slow-to-Recover (STR) Program for adults with ABI and high care needs revealed significant cost savings associated with community based care. This program provided individualised funding to enable access to attendant care,
health and therapy services, inpatient rehabilitation and accommodation, equipment, administration and case management services to support injured adults to transition out of high cost acute care beds. In 2002/03 the cost of supporting an ABI:STR client to live in the community was $80,220-$920 per annum\textsuperscript{15}, which was significantly less than the $500 per day required to support a prolonged stay in a hospital based unit at that time.

Coordinated cross-government planning to support streamlined transitions through the rehabilitation continuum is pivotal to improving the cost efficacy of the current system and ensuring optimal outcomes for adults with ABI and their family members. The establishment of a state-wide strategic planning group comprising of representatives from key government agencies including Queensland Health, Department of Communities, Disability Care Australia, CRS Australia, service providers, advocacy groups, and people with brain injury and their families is recommended as a key first step towards designing a seamless and cost efficient service system and addressing the key recommendations outlined below.

**KEY RECOMMENDATION #2**

**There is a need for increased government investment in developing a range of accommodation and support options for adults with brain injury residing in metropolitan, regional and rural areas of the state.**

This recommendation recognises the persistent challenges of residential housing availability, access and support for adult survivors of ABI. The housing solution for people with ABI is uniquely tied to the level and type of disability support provided. As reported by Synap (2012), a peak brain injury body of Queensland, ‘the type of accommodation a person will need following acquired brain injury will depend on the level of support required to maintain quality of life’. According to Synap, the housing options available to a person with ABI and their family may be impacted by a number of critical factors including;

- Funding available to the person (access to insurance)
- The family’s social support network
- Capacity of the family to look after the person in the home
- Services available in the area
- Level of support (full time or occasional) a person requires and community groups who can provide in-home support

Locating appropriate community accommodation and support for adults under 65 years of age with complex health conditions (e.g., multiple sclerosis, traumatic brain injury, cerebral palsy) is a current challenge facing the disability, health and aged care sectors in developed countries. In Australia, the population of adults aged between 18 and 65 years of age with long-term high support needs
generally have few appropriate housing and support options following serious injury or illness. For this reason, these young adults can experience a protracted length of stay in inpatient or slow to recover rehabilitation units, or face admission to residential aged care. In a single year (2009-10), there are almost 150 young adults (aged 18-50 years) being admitted to residential aged care nationally (Qld=23, NSW=47, Vic=35).

Statistics from the AIHW (2011)\textsuperscript{16} indicate that the demand for accommodation services (including housing stock and support services) is increasing. Table 2 below indicates that in the period of 2009-10, Queensland reported the third highest number of people with serious injury or illness accessing accommodation services from institutional settings (e.g., 24/7 care environments such as hospital and larger health facilities) through to community settings (e.g., small group homes). Overall, the majority of people (73%) with permanent injury or illness requiring accommodation services in Queensland are reported to access community settings over and above all other forms of accommodation support. This figure also likely reflects the low to moderate severity of disability that would enable people to live more independently in the community with adequate home-based, occasional support.

**TABLE 2: Users of accommodation support services (highest ranking states nationally) 2009-10**

<table>
<thead>
<tr>
<th></th>
<th>NSW N(%)</th>
<th>VIC N(%)</th>
<th>QLD N(%)</th>
<th>SA N(%)</th>
<th>TOTAL (Australia)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Institutional</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>accommodation</td>
<td>1700 (18.3%)</td>
<td>357 (2.5%)</td>
<td>849 (13.3%)</td>
<td>682 (13.4%)</td>
<td>4174 (10.5%)</td>
</tr>
<tr>
<td><strong>Group homes</strong></td>
<td>4437 (47.7%)</td>
<td>4720 (33.1%)</td>
<td>1020 (16.0%)</td>
<td>1040 (20.5%)</td>
<td>13435 (33.7%)</td>
</tr>
<tr>
<td><strong>Other community</strong></td>
<td>3340 (35.9%)</td>
<td>9281 (65.1%)</td>
<td>4650 (72.7%)</td>
<td>3504 (69.1%)</td>
<td>23024 (57.7%)</td>
</tr>
<tr>
<td><strong>settings</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>9297 (100%)</td>
<td>14257 (100%)</td>
<td>6394 (100%)</td>
<td>5074 (100%)</td>
<td>39854 (100%)</td>
</tr>
</tbody>
</table>

*Source: AIHW, 2011*

Throughout many states in Australia (e.g., Queensland, NSW, Victoria, Western Australia), action is increasingly centred on providing greater housing choice for the adult population under 65 years in line with general community expectations\textsuperscript{17}. Apart from the availability of housing options, research evidence indicates that there is value in returning home for people with brain injury, where accommodation change (from hospital to home) has been found to exert a positive impact on transition success\textsuperscript{18}.

Further Queensland-based research conducted at Griffith University into the experience of community-based supported accommodation identified the following elements for future accommodation planning:
The experience of place for young people with complex care needs is determined by relationships within place (including with paid support staff, family, housemates).

Several key elements of place (accessible and aspirational design, flexible care and support services that meet individualised need; freedom and self-expression, defining roles and ownership of space) were highlighted as important factors in purpose-built accommodation located in the community for people no longer able to be cared for at home.

Multiple housing and support options, driven by consumer choice and cross-sector collaborations are required

A continuum of support options is important for the changing abilities and life stages of a young client group.

Without general options for housing available, there are reported trends towards transinstitutionalisation or place shifting – place shifting can be defined as the misplacement of people moving out of institutionalised environments to equally restrictive environments, such as individuals held in custodial care due to lack of accommodation options; individuals kept in acute care hospital beds due to lack of accommodation options; individuals remaining in long-term mental health facilities due to lack of accommodation options. This place shifting is due to a variety of reasons, including a slowing trend of deinstitutionalisation particularly for ‘harder to place’ individuals with complex support needs, lack of coordination between housing and disability policy frameworks resulting in separatist and discontinuous housing pathways, and political counter-currents.

Carer in-home support: While the Young People in Residential Aged Care (YPIRAC, Australian Government) initiative successfully diverted some (n=207 in 2009-2010) young people from entry to residential aged care, the high prevalence of adults with ABI (26%) being cared for in the home by co-resident primary carers over the age of 65 in Australia is anticipated to increase the demand for viable alternatives to residential aged care placement in the future. The Australian Institute of Health and Welfare (2007) identified that in 2003 only 8% of people aged under 65 with ABI and a severe or profound activity limitation were living in cared accommodation, with the remainder living in households. As primary carers age, the need to plan for future care environments, in addition to supporting families to continue caring for relatives at home, is becoming more of a concern for service providers and all levels of government.

For people with disability receiving cared support at home (AIHW, 2011), two thirds of all disability users with an informal carer reported that the carer was their mother (77907 persons in Australia). Mothers aged 65 years and over comprised three quarters of all older carers of service users aged between 25 and 64 years. Almost 1 in 10 reported that their carer was their spouse. These
statistics demonstrate that regardless of the type of accommodation or level of permanent injury or illness, the carer is an important component of the housing/in-home support solution. Readily accessible, affordable housing, in combination with flexible and individualised support, is required to support transitions to more independent living environments or those offering additional support as care needs change. Additionally, the targeted provision of support to families during the period of transition from hospital to home, and on an ongoing basis, is also recommended.

**RECOMMENDATION #3**

**Development of specialist state-wide community rehabilitation and case management services, and adequate supports for participation, is required to promote the optimal health and wellbeing of both adults with brain injury and their family members.**

Supporting people with brain injuries to actively participate in home and community life is integral to their health and wellbeing and that of their families⁶,²⁰, and is a key aim of community based rehabilitation²¹. Despite expertise in acute medical treatment and emergency retrieval in adult brain injury rehabilitation in Queensland, there are notable gaps in the provision of community-based brain injury rehabilitation and case management support. Specialist services in most parts of the state focus on acute medical care and hospital based rehabilitation service delivery, with limited funding and resources available for community based support. Subsequently people with brain injury and their families may receive limited specialist support during the critical period of transition to community living. Recent Queensland based research found that difficulties accessing therapy were associated with a less successful transition experience for adults with ABI¹⁸. The establishment of specialist community rehabilitation and case management services throughout the state is required to ensure adequate support during transitions to the community and in the years following discharge home.

**Community Based Rehabilitation:** Currently adults with brain injury leaving Queensland hospitals may be referred to Community Based Rehabilitation teams which were established to deliver time limited, generic community based therapy services (between 8 and 12 weeks) for adults with a variety of health conditions exiting hospital. However, adults with brain injury often require a longer period of rehabilitation to optimise their recovery, and those with complex care needs or challenging behaviours may be excluded from accessing these services. Access to specialist community based therapies and therapy support is essential to promoting optimal outcomes and community participation for adults with brain injury. The provision of specialist community based therapy, paid care and other intervention services ‘when needed’ has been shown to significantly decrease daily care needs and reliance on family care, with associated reductions in long term care costs²².
Access to ABI-specific community rehabilitation services is actively supported within other Australian jurisdictions. In a current University of Queensland study, representatives from the Transport Accident Commission and regional ABI case management services in Victoria expressed a preference for using specialist community based therapists who were perceived to achieve better outcomes for their clients, helping to prevent functional deterioration and increased care costs over the long term. Similarly, in NSW, a coordinated state-wide network of specialist community based therapy services has been operating throughout metropolitan and regional areas for the past two decades. Within both jurisdictions, specialist therapists are funded to travel significant distances via road and air transport to deliver specialist services to people with brain injury and their families living in rural and remote communities. The development of similar specialist community rehabilitation services throughout the state is required to improve the outcomes of adults with ABI in Queensland.

Case Management services in the community: Access to coordinated case management services and early mental health assessments, particularly for clients with neuro-behavioural difficulties, is critical in the delivery of community based rehabilitation. Active case management support is required to respond proactively to diverse and changing care and support needs, and negotiate access to services provided by a number of different government departments, NGO and private sector providers.

People with brain injury and their families involved in the STEPS consultation process highlighted the importance of case management (or similar) support, throughout all stages of the hospital to home continuum, including within the first few weeks of injury, and throughout hospital admissions and the period of transition to the community. This level of support is currently available in other Australian states, with specialist brain injury case management services available at a metropolitan and regional level throughout NSW and Victoria. Access to specialist case management support in Queensland is limited by resource restrictions, with ABIOS only able to provide ongoing case management support to those living in the south east corner of the state. The development of specialist case management services in regional areas is required to meet the discreet support needs of those living in other areas of the state.

Vocational services: Participation in vocational and educational roles is strongly associated with social integration and life satisfaction after brain injury. However, employment rates after severe brain injury are generally low, ranging between 25 and 65% in published studies. There is good evidence that specialist brain injury programs for vocational rehabilitation are effective in improving return to work outcomes. In Queensland, the establishment of a specialist vocational rehabilitation service for people with brain injuries living in Brisbane by CRS Australia has helped many people return to study and paid employment roles. However, further development of specialist service capacity in Brisbane and other regions throughout the state is recommended.
Supports for Participation: Research involving adults with brain injury in Queensland has consistently highlighted the need for an increased focus on participation as a goal of rehabilitation, particularly for those with more severe injuries. Participation in vocational, educational and/or recreational activities is associated with improved life satisfaction, psychological health and quality of life after brain injury. The provision of ongoing support for participation is pivotal to the delivery of community based rehabilitation services, with QBISM members reporting that even a small amount of paid carer support for community access can result in significant improvements in the quality of life of people with brain injury and their family members.

Supporting participation may do little to minimise daily care costs in the short term, however a focus on participation can significantly reduce the long term costs of severe traumatic injury. Cairns, Dyson, Canobi & Vipond reported that a focus on participation outcomes in the New Zealand ACC scheme National Serious Injury Service (NSIS) was a key element in delivering a $820 million actuarial release (cumulative over two years) as a result of cost containment within the scheme. They highlighted that ‘the flow on affect of participation is a reduction in the growth of attendant care cost’ (p. 38), providing sound economic incentives for supporting participation after ABI. Australian researchers have also found that familial carers are significantly less distressed when relatives with brain injury participate in activities in the community. Hence, supporting participation and the development of a range of flexible respite options is both economically and socially desirable.

**RECOMMENDATION #4**

**There is a need for increased government investment in building specialist service capacity in regional, rural and remote communities.**

A localised continuum of specialist inpatient, outpatient, and community based rehabilitation and case management services is currently lacking in most areas of Queensland. This poses significant barriers to service access for people with brain injury and their families residing in regional, rural and remote communities. In 2012, the National Rural Health Alliance estimated over a third (about 34%) of patients admitted to Australian hospitals with traumatic brain injuries in 2004-05 were rural and remote residents. In the absence of clear clinical pathways, and localised services, many of these people and their families potentially struggle to access the services and supports needed to promote optimal recovery and return to their local communities. Those relocating to metropolitan areas to access specialist services can experience financial hardship due to increased cost of living pressures, loss of employment, and dislocation from existing informal networks of support.

Brain injury rehabilitation services must be able to respond appropriately to the needs of people from rural and remote communities, particularly those from...
Indigenous and Torres Strait Islander communities, ‘for whom sense of self is strongly related to sense of location and land, and core beliefs are grounded in the person’s land’ (NHMRC, 2008, p.38). ABIOS and Synapse have developed innovative models of service delivery in partnership with people from indigenous backgrounds in some regional, rural and remote communities in Queensland. ABIOS has partnered with Aboriginal and Torres Strait Islander communities since 2006 to look at the most appropriate brain injury community rehabilitation model. A service model based on Community Based Rehabilitation (CBR) principles has been developed out of this work and has subsequently been endorsed by key stakeholders in Indigenous health and disability agencies. Resource development, including a Training Programme for Aboriginal and Torres Strait Islander Health Workers, has also been an outcome of these partnerships. Synapse has fostered similar partnerships, and is currently developing an eight bed transitional rehabilitation facility for indigenous adults with brain injury in the Cairns region (The Wabu Gadun Bulmba Gurriny Mukanji Centre). This FaHCSIA funded project will initially support the transition of eight indigenous adults who have resided in Cairns Base Hospital with length of stay figures in excess of 1,200 days, resulting in a projected cost saving of $16 million over four years for Queensland Health. Importantly, the project will help to reconnect clients with ‘their land, their culture, and their people’.

While local service development projects have helped to improve the accessibility of specialist services in some regional communities, sustained investment in capacity building is required. Participants in the 2010 ABI Rural & Remote Challenge Forum identified a wide range of priorities for specialist service development in regional communities including:

- Increased inpatient rehabilitation beds in regional areas
- Development of regional outreach services including case management support and counselling services for adults with ABI and their family members
- Increased linkages of services through the development of local information hubs
- Improved access to individualised support funding
- Improved access to community based rehabilitation services
- Specialist skills development in regional areas
- Development of a range of accommodation options
- Improved access to integrated mental health services, and
- Development of a state-wide data base for ABI.

The value of sustained investment in capacity building in regional areas is well documented in Australian research. It is widely recognised that people from rural areas generally have poorer health outcomes than those living in urban centres. However, studies in NSW and Victoria, which both have state-wide networks of localised brain injury services have found comparable rehabilitation outcomes for rural and urban residents with ABI.
The National Rural Health Alliance recommends that regionally based brain injury rehabilitation services ‘should be integrated and resourced as part of a State-wide approach’ (p 9). They have recommended the establishment of regional service hubs which provide rehabilitation and outreach support to people with ABI from rural and remote areas. Significant investment in service development and infrastructure supports across the state, in addition to the development of a state-wide ABI service plan is required if this aim is to be realised in Queensland.

**RECOMMENDATION #5**

The systematic collection and analysis of data related to post injury pathways, service utilisation costs and outcomes after injury is required to design a responsive, cost-efficient state-wide service system.

There is no current data base which records individual trajectories through the service system or long term outcome after acquired brain injury. Subsequently, the evidence base for strategic planning to better meet the needs of people with brain injury and their families in Queensland is not well developed.

The 2006 state trauma plan recommended the development and maintenance of a centrally coordinated minimum data set as an essential component of effective injury management reporting:

‘Data is an essential element of the trauma system. It supports not only the setting of a strategic direction but also informs quality control of the system, research and education. The development of an integrated data collection and information exchange system would not only contribute to the effectiveness of the system but also has the possibility of reducing the overall costs of the system.’ (A Trauma Plan for Queensland, p.39)

The report identified five separate data bases which collected data related to traumatic injury, with no corporately endorsed mechanism for data sharing. These included the Queensland Trauma Registry, and data bases developed by Queensland Transport, Queensland Police Service, Queensland Ambulance Service and the National Centre for Classification in Health. Funding for the Queensland Trauma Registry has subsequently been withdrawn.

Establishment of a minimum data set for brain injury would enable identification of opportunities for improving cost efficiencies within the current service system, improved management of post injury pathways, and identification of discreet areas of unmet need. Systematic analysis of such data in other Australasian jurisdictions has supported strategic service planning to improve trauma management systems, and ultimately reduce long term care costs and improve functional outcomes after serious injury.
The development of a state-wide data base to track the rehabilitation trajectories and long term outcomes of adults with ABI in Queensland is recommended. Consideration of incorporating ‘opt out’ consent processes, such as those existing in the Victorian State Trauma Registry is recommended to facilitate ongoing data collection and research to improve systemic responses to the needs of adults with ABI and their family members. Close collaboration with other Australian states and territories in developing consistent data sets to enable cross-jurisdictional benchmarking, and reference to existing international minimum data sets, such as those maintained by the New Zealand ACC and the US TBI Model Systems of Care National Data and Statistical Center is also recommended.

CONCLUSIONS

Brain injury represents a whole-of-life and whole-of-person condition that demands a whole-of-system response. Rehabilitation represents one of the most complex and integrated forms of health care which involves the timely delivery of multiple services via multiple disciplines in different care settings over a lengthy period of time.

Each of the recommendations identified in this paper pertains to a component of quality brain injury rehabilitation, and together, forms a coherent brain injury response. Multiple previous reviews have called for the development of a coordinated response to the rehabilitation and support needs of adults with ABI living in Queensland, including:

- A Trauma Plan for Queensland 2006
- Queensland State-wide Rehabilitation Medicine Services Plan 2008-12

Coordinated state-wide ABI service planning is pivotal to addressing the cost inefficiencies of the current service system and improving the outcomes of adults with ABI and their family members in Queensland. The QBISM calls on the Queensland and Commonwealth governments to progress the establishment of a state-wide strategic planning body and the development of a state-wide ABI service plan to enable integrated service planning, improve post injury pathways and address the fragmentation and cost inefficiencies of the current service system.
STATISTICAL SOURCES


DEFINITIONS

Adult Acquired Brain Injury: An acquired brain injury, as defined by the Australian Institute of Health and Welfare, refers to any damage to the brain that occurs after birth. This position paper pertains to the service and support needs of adults (aged 18 years and over) with ABI in Queensland.

Rehabilitation: The British Society of Rehabilitation Medicine has defined rehabilitation in both conceptual and service terms. Conceptually, rehabilitation is ‘a process of active change by which a person who has become disabled acquires the knowledge and skills needed for optimal physical, psychological and social function’ (p. 7). Rehabilitation, as a service, refers to ‘the use of all means to minimise the impact of disabling conditions and to assist disabled people to achieve their desired level of autonomy and participation in society’ (p.7).

Early and sustained access to intensive rehabilitation after ABI helps to reduce disability, restore function and improve participation. Evidenced based guidelines for rehabilitation after ABI identify four distinct phases of rehabilitation, including preventative interventions delivered during acute care admissions, post-acute (sub-acute) rehabilitation which is delivered in specialist inpatient or residential rehabilitation units, community based rehabilitation, and longer-term community support. Evidence based guidelines emphasise that rehabilitation pathways after brain injury are not linear, and may vary considerably dependent on individual rehabilitation needs. Different individuals require different services at different stages in their recovery. Subsequently, services need to be re-accessible, and coordination and communication between different services along the rehabilitation continuum is an essential component of effective rehabilitation. Access to multidisciplinary teams with specific expertise in brain injury rehabilitation improves long term outcomes, decreases care needs and has the potential to significantly reduce long term care costs.
REFERENCES


8. National Disability Insurance Scheme Act 2013 (Australia)


32. National Health and Medical Research Council (2008). *Ethical Guidelines for the Care of People in Post-Coma Unresponsiveness (Vegetative State) or a Minimally Responsive State*.


<table>
<thead>
<tr>
<th>Location of Care</th>
<th>Acute Hospital Unit</th>
<th>BIRU</th>
<th>Slow-to-Recover Unit</th>
<th>Supported Accommodation (group home)</th>
<th>Home with paid care + ongoing therapy&lt;sup&gt;1&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approximate Cost per week</td>
<td>$8400</td>
<td>$8400</td>
<td>$3500 - $3950</td>
<td>$2350 - $3450</td>
<td>$3350&lt;sup&gt;2&lt;/sup&gt; - $6200&lt;sup&gt;3&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

<sup>1</sup>Based on estimate of 6x1hr sessions of private therapy per week

<sup>2</sup>Based on estimate of 8 hrs care per day/7 days per week

<sup>3</sup>Based on 24/7 paid care/7 days per week