ACI NSW Agency for Clinical Innovation

Brain Injury Rehabilitation Directorate

Diagnostic Report

Model of Care

NSW Brain Injury Rehabilitation Program

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Executive Summary

Traumatic brain injury (TBI) is the most common cause of death and disability among young people in NSW. The impact of a traumatic injury on the brain ranges from concussion to persistent vegetative states and is typically classified from mild to very severe, according to the duration of unconsciousness (coma) and the duration of post traumatic amnesia (confusion) in hours/days and even months. In the most severe forms TBI can have long-term, lifelong social participation consequences.

Since the mid-70s dedicated systems of TBI rehabilitation services have been established both internationally and in Australia. It was recognised that advances in medical technology meant that survival rates for people with TBI were improving and services were needed to prevent many younger people being shifted to nursing homes or psychiatric institutions with little or no rehabilitation.

The consequences of brain injury extend beyond the purely clinical, which themselves can be very serious – they can have profound implications for relationships, ability to work and learn, participation in society and overall quality of life.

The NSW Brain Injury Rehabilitation Program (BIRP) was established more than 21 years ago as a best practice model of specialised rehabilitation with NSW Health governance, in partnership with the Motor Accident Authority of NSW. The funding comprised an initial capital outlay for infrastructure, staff and resources; supported by a part funding revenue stream that was initially quarantined for 7 years to support establishment of specialised brain injury rehabilitation services. It was decided to review the BIRP Model of Care because it has not been formally reviewed since the commencement of services and the context in which it operates has changed significantly.

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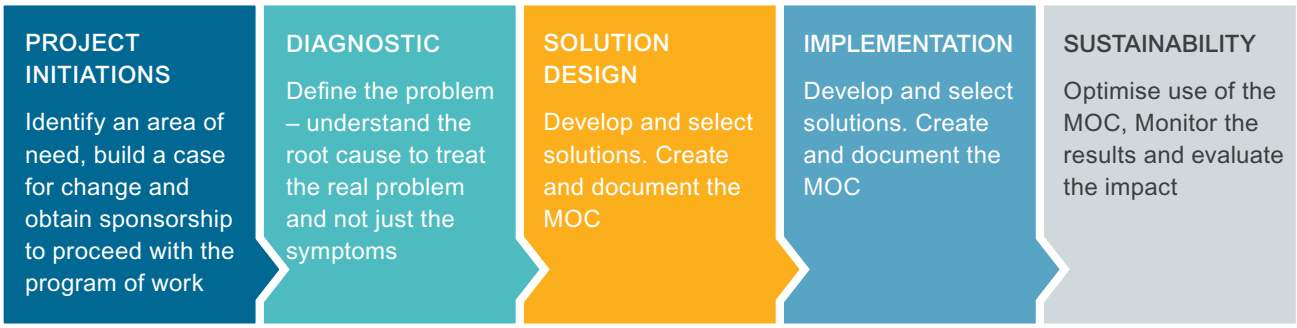

Methodology

ACI uses a project management methodology comprising five stages to review and develop Models of Care. This process was used in developing the NSW Rehabilitation Model of Care with six settings in which rehabilitation occurs and eight principles of care being defined. A contributing factor for the current BIRP Model of Care review is that specialist rehabilitation services (e.g., brain, spinal cord and burn injuries) were excluded from the general rehabilitation Model of Care methodology.

This report documents the diagnostic stage of the Model of Care process. The diagnostic phase consisted of a literature review, service mapping (including survey of BIRP services followed by visits to the services), data analysis, key stakeholder and patient consultations and this report. A Model of Care steering committee was convened by ACI for oversight of the whole Model of Care review process.

BIRP Services: As is

There are 15 dedicated specialised rehabilitation services for both adult and paediatric clients with traumatic brain injury (TBI) that comprise the NSW Brain Injury Rehabilitation Program (BIRP). Metropolitan and rural services are located in specific Local Health Districts (LHDs) providing hospital and community-based services across defined areas of NSW and the ACT.
Ten dedicated specialised rehabilitation services are located outside of the Sydney metropolitan area.

FIGURE 4 BIRP Adult Network of Services

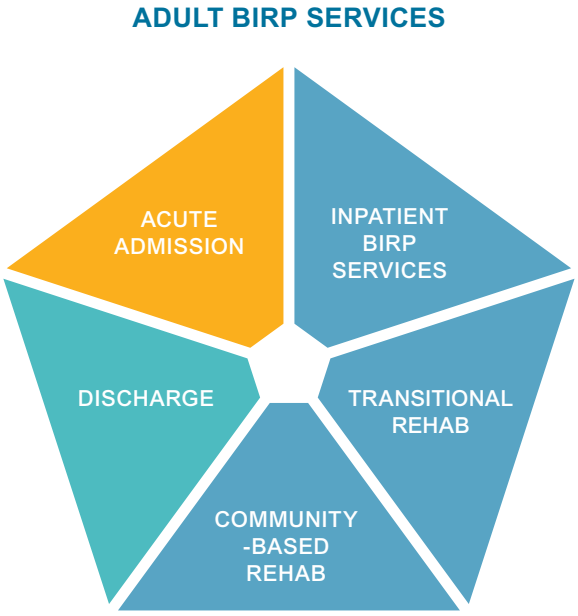

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FIGURE 5 BIRP Paediatric Network of Services

Admission criteria

- Age: generally clients aged 16-65 years are admitted to adult BIRPs and paediatric BIRPs admit clients with trauma from after birth and while still at school
- Injury severity: generally clients admitted to adult services have suffered a severe to extremely severe TBI, particularly inpatient units although clients with complex mild or moderate injuries can be admitted to non-inpatient services. Paediatric clients however are admitted with all levels of injury severity
- The client or significant other/s lives in the area covered by the BIRP delivering the needed service/ programs. Each of the three adult inpatient units and the three paediatric in-reach services cover about a third of the state each while other programs have supra regional roles.

Rural BIRPs provides access to services close to where the person and their family live and are linked with referring BIRPs and treating hospitals. The intensity and type of intervention can be limited by distance and travel time in some areas of NSW.

The TBI population group

- The incidence of TBI peaks in the 15-35 years age group
- The estimates of incidence for adults admitted to hospital for TBI is about 150 per 100,000 population per year and the incidence for children 0-15 years admitted to hospital with significant head injury was 75 per 100,000.
- In the under 65 year age group the ratio of patients is 3.4 males to 1 female, a differential largely thought to be related to risk-taking behaviour among young males
- Motor vehicle-related trauma accounts for about two-thirds of moderate and severe TBI, with falls and assaults being the next most common causes
- About 50% of the adult and paediatric BIRP populations have 1 or more challenging behaviours following TBI
- Mental Health, Drug and Alcohol issues are common co-morbidities both pre and post TBI and are a contributing factor for the presence of challenging behaviour.
- In 2012 there were 6.3% indigenous client admissions to BIRP services with 45 males and 25 females
- In 2012, 5-14 year olds (21%) and 15-24 year olds (23%) accounted for a large proportion of all BIRP client intakes, a similar proportion to previous years
- The prevalence of mild TBI is likely to be underestimated due to classification and diagnostic errors and because a large proportion of people with mild TBI do not present to hospital
- In 2008 the total cost of TBI in Australia was estimated to be $8.6 billion, comprising:
  - costs attributable to moderate TBI ($3.7 billion) and severe TBI ($4.8 billion)
  - financial costs ($3.7 billion) and burden of disease costs ($4.9 billion)
- Employment rates post TBI differed across the 11 BIRP regions, ranging from 16.7% to 42.9% (average 29%) and there was a marked and consistent post injury shift from full-time to part-time employment.

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A critical aspect in the evolution of specialised TBI rehabilitation was the expansion of the physical rehabilitation focus to include cognitive, behaviour and community elements into Models of Care. General rehabilitation services primarily treat an older age group (in 2012 only 5% of acute stroke admissions were aged under 45) with a focus on physical impairments and not geared to meeting the extent and duration of intervention to manage the social, cognitive and behavioural challenges of the predominantly young (15-35) male population characteristic of TBI. Early intervention and specialist rehabilitation services were aimed to maximise recovery following trauma and effectively manage the distinctly different challenges that often confront people with TBI and their families.

People requiring specialised brain injury rehabilitation tend to be younger and healthy with a need for a broader focus to meet ongoing cognitive and psychological needs within the family and social contexts. This requires an integrated continuum of rehabilitation and support, sometimes over many years.

Findings

The consumers, consumer organisations and service user representatives consulted noted that overall, the Model of Care was generally regarded as best practice with a highly skilled specialised approach that benefited from the state-wide network of services and professional development of staff.

While there are mechanisms for client input and feedback on services, further consumer consultation is required to better understand the patient and family experience.

Consumer representatives, along with a number of BIRP clinicians saw an obvious need for a more structured and systematic approach to support engagement at all levels of the clinical network so consumers are active partners in policy and decision making structures.

Strengths reported from stakeholder consultations of the current service model included:

- The value to clients and families of having a specialist rehabilitation service and being able to return to the service when needed.
- The client and family centred approach provided by the BIRP
- The goal-oriented approach underpinning service delivery, that includes specialised case management as a core component of the rehabilitation program
- The active commitment to an interdisciplinary Model of Care involving skilled and experienced health professionals
- The spectrum of services in BIRP that spans inpatient through to longer-term community-based rehabilitation across metropolitan and rural teams
- Having specialist adult and paediatric streams within the program
- The involvement of families and carers in service planning and delivery
- The networking, service development and professional development role of the ACI Brain Injury Rehabilitation Directorate.
- Centralised area of knowledge
- BIRP staff provide training to support staff
- Helpful point of contact
- Client needs are identified and provided (e.g., equipment and care needs) prior to discharge

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Summary of issues and potential opportunities for improvement:

- Documentation of the Model of Care lacks cohesion and is not easily accessible
- Funding complexity and inequities across NSW impact on meeting client needs
- Variation in staffing for similar client populations and BIRP settings of care impacts on service availability, particularly in rural and remote NSW
- Lack of culturally appropriate TBI information, rehabilitation programs and resources to support Aboriginal clients and their extended families in hospital and after a return home
- Variable processes and resources to support 15-24 year olds, including leaving school and transition to adult services
- Limited policies of consumer engagement that delivers meaningful involvement of end users in service planning as well as service delivery
- Limited professional development opportunities specific to brain injury rehabilitation, teamwork; and working with complex clients and families
- Limitations in using information technology in everyday practices
- Low 'profile' of BIRP in comparison to other high volume health groups.
- Transfer of care and distance are barriers to accessing services close to where the person lives
- Variation in application of the BIRP eligibility criteria
- Delays in initiating referrals to BIRP and limited in-reach to adult acute setting
- Timely and equitable access to BIRP services at key points in the recovery and rehabilitation continuum
- Lack of dedicated inpatient rehabilitation beds for paediatric BIRPs
- Variation in resources available for different Transitional Living Programs can limit client access and family engagement
- Inequitable access following hospital discharge to integrated outpatient BIRP rehabilitation
- Inequitable access following hospital discharge to multi-disciplinary community therapy limits availability of specialised rehabilitation needed for recovery and improved client outcomes, particularly in rural and remote NSW
- Lack of low cost carer/family accommodation close to services, particularly for Aboriginal clients in hospitals distant from their family/communities
- Limitations in Transfer of Care to non-health community services.
- There is a lack of clarity about the relationship between the collection of BIRP clinical outcome data and what may be the clinical outcome indicators for reporting under ABF so that funding levels are maintained into the future

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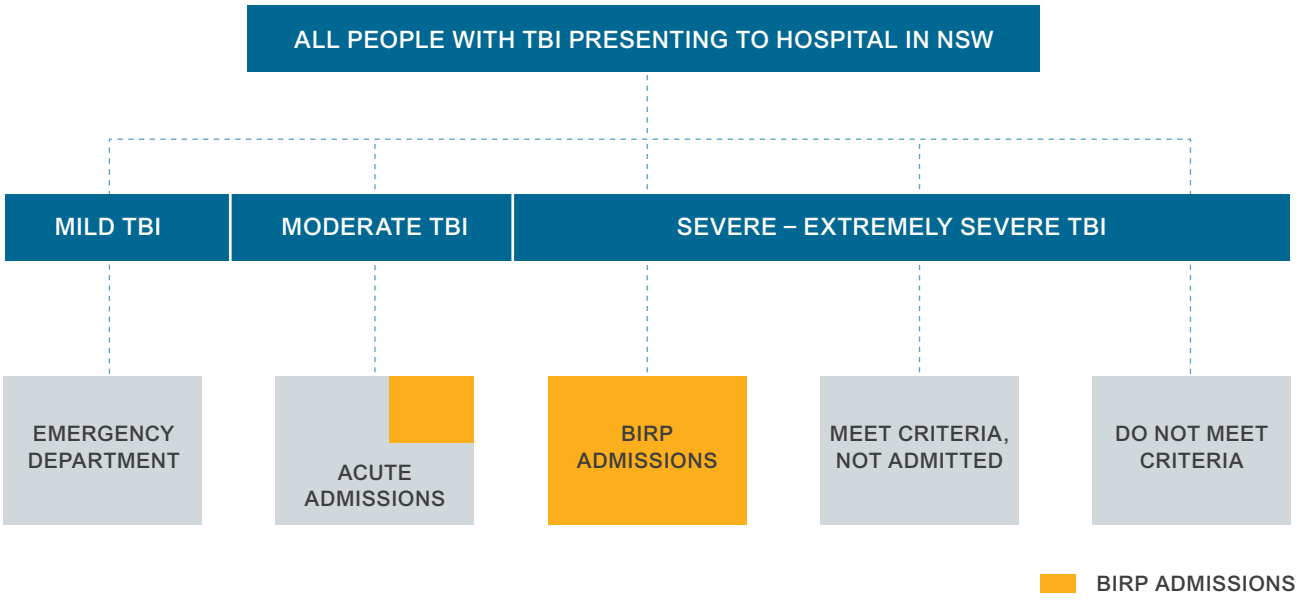
FIGURE 6 Change in Model of Care scope



Change of scope and further diagnostic work

The scope of this project was to review the Model of Care for specialist BIRP services. However, key issues raised across most of the consultations covered the whole journey of a person following a TBI. Under the initial scope, those with mild and moderate injuries, those over working age and people who may meet criteria but are not admitted to BIRP services were not consulted in the current BIRP Model of Care review.

The consensus of the Model of Care steering committee convened at the beginning of the diagnostic project, and indeed of the majority of stakeholders consulted, was that the scope should be expanded to create a Model of Care framework for all people with a TBI admitted to hospital. The Model of Care framework would include people of all ages with mild, moderate and severe traumatic brain injury, clearly define the current pathways and identify solutions to any issues for these groups.

Figure 6 demonstrates the people with TBI that were the focus of the current Model of Care review. A staged approach is proposed to developing an expanded framework for the TBI Model of Care, starting with people with severe TBI to build on the work completed with BIRP services in the current diagnostic project.

Recommendations

- Utilise the Diagnostic Report to move to the solution design phase of clinical redesign. Gaps and areas for improvement can then be identified for stakeholder consultation to improve different aspects of the BIRP Model of Care for service planning and delivery.
- ACI to convene a working group involving Australian Rehabilitation Outcomes Centre, ACI Health Economics and Evaluation Team and BIRP representatives. The purpose is to explore the data to better understand the severe TBI population, hospital flow and patient related outcomes. This will be useful in identifying how funding levels can be maintained into the future for finalising the BIRP Model of Care.
- In consultation with key stakeholders formally document the BIRP Model of Care so that it builds on existing knowledge, clinical practice and an understanding of children, young people and adults under 65 years and their families following admission to BIRP services. The BIRP Model of Care will clarify referral and acceptance criteria, provides clear access and pathways information and provides for a more integrated, cohesive and coordinated service system.
- To implement a measurable consumer engagement policy, at both state and local levels, that delivers meaningful involvement of end users in service planning as well as service delivery.
- ACI commission a diagnostic project to better understand factors influencing decision making for clients who fit BIRP criteria and are not referred or admitted; those who do not fit criteria but are referred with some admitted.
- ACI to initiate a clinical redesign project to develop a framework for all people, regardless of age, who present to hospital following a TBI with any level of injury severity.

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1. Introduction

Since the mid-70s dedicated systems of TBI rehabilitation services have been established both internationally and in Australia. It was recognised that advances in medical technology meant that survival rates for people with TBI were improving and services were needed to prevent many younger people with TBI being needlessly shifted to nursing homes or psychiatric institutions with little or no rehabilitation.

General rehabilitation services primarily treat an older age group (in 2012 only 5% of acute stroke admissions were aged under 45[1]) with a focus on physical impairments and not geared to meeting the extent and duration of intervention to manage the social, cognitive and behavioural challenges of the predominantly young (16-35) male population characteristic of TBI,[2,3]. In addition, where older persons admitted to general rehabilitation service commonly have impairments in functions of the cardiovascular, haematological; immunological and respiratory systems there is typically an absence of these medical co-morbidities for younger people with TBI.

As a part of this movement, the NSW Brain Injury Rehabilitation Program (BIRP) was established more than 21 years ago as a selected specialty service to supplement general rehabilitation programs. Early intervention and specialist rehabilitation services were aimed to maximise recovery following trauma and effectively manage the distinctly different challenges that often confront people with TBI and their families during the stages of recovery, rehabilitation and social integration. The 1987 Cuff Report[4], which led to the establishment of the BIRP, noted a number of factors that necessitated a specialised program:

- The disability associated with brain injury is profound and multi-faceted and can result in patients becoming a ‘different person’
- People 15-34 years of age incur most TBI and in the most severe forms this can have long-term, lifelong social participation consequences
- The consequences of brain injury extend beyond the purely clinical, which themselves can be very serious – they can have profound implications for relationships, ability to work, participation in society and overall quality of life.

A critical aspect in the evolution of specialised TBI rehabilitation was the expansion of the physical rehabilitation focus to include cognitive, behaviour and community elements into Models of Care. Linked to this there has been the development of international guidelines and benchmarks for the provision of best practice in TBI rehabilitation (e.g., Accident and Compensation Commission 2006[5]; Bayley et al, 2014[6]; Maas et al 2008[7]; UK National Institute for Health and Clinical Excellence 2014[8]). These guidelines are predicated on the research evidence that people with TBI who receive care in specialist services achieve more positive outcomes over the short and long-term, with correspondingly lower levels of morbidity.

A TBI has a profound impact on a person and may limit their ability to benefit from rehabilitation, participate in the rehabilitation plan and follow through with agreed actions because of reduced memory, initiative, organisation and planning skills. People with TBI might talk about wanting to get better and not be able to independently use rehabilitation strategies to do what is necessary to get better. They may forget their appointments, they will forget to take their medication and they will forget or not be able to independently use the strategies that have been taught to them. In general hospital settings individuals can be loud and noisy, socially inappropriate and even sexually disinhibited, without the skills to understand and manage the impact on others.

The mechanism of the injury itself is a key factor in what makes rehabilitation different for people with TBI from other neurological brain injury. In TBI there is an external force from an accident or trauma that may result in the brain being penetrated by objects, cut by internal bony skull ridges, torn, stretched, bruised or become swollen from the twisting and shearing forces as the brain moves around inside the skull or is squashed when the skull is compressed or split open. Some brain cells will die while others recover partially or completely and the pattern of intact cells will be quite scattered. Depending on the type and velocity of the forces affecting the brain, different areas throughout the whole brain are affected. This is different from stroke where a clot prevents oxygen travelling to the cells supported by that blood vessel or where a blood vessel might burst and affect the immediate area and possibly the area distal to the bleed if the blood supply is cut off. The damage is limited to the area of the brain supplied by that vessel (e.g., middle cerebral artery) and other areas remain intact.

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In the early stages of recovery following brain trauma can be a period of confusion called post traumatic amnesia or PTA. The duration of PTA is a determining factor for injury severity, and is only present following TBI. This stage of recovery is best managed by skilled nursing medical and allied health staff in a safe, controlled ward environment or by providing additional staffing. This prevents escalation, transfer to mental health services or inappropriate discharge. The correct medication at the right time can be very useful in managing symptoms of PTA. Using sedation or other medications to keep the person calm may exacerbate the behaviour and mask the symptoms of recovery and injury severity. PTA is often associated with aggressive and abusive behaviour with the person behaving quite differently from usual. Patients often don't recognise family and don't understand that they are in hospital. Orientation to person, place and time indicates when the person emerges from PTA and the patient behaviour usually settles.

Many of the things we do depend on the interconnections between the brain and body. Several different areas of the brain often work together when carrying out different functions. In situations where the interconnections are not operating correctly a person may have difficulties with performing that function. The pattern, impact and the extent of areas of the brain affected by an external force will be very individual, even though the injury itself may appear the same. This is due to a variety of factors such as injury severity, areas of brain affected as well as brain maturity and person's age. Unlike other acquired types of brain injury, after a TBI there is an expectation of continuing recovery of brain function, typically occurring in the first 2 years. This provides a window of opportunity for specialised rehabilitation intervention to maximise recovery, health and social participation outcomes. However, TBI may result in limitations of an individual's daily activities and restrictions in participation in life situations, leading to an overall decrease in perceived quality-of-life. Over time, functional improvements may occur although residual impairments and disabilities may prevent optimal community reintegration. The person can have lifelong disabilities in communication, physical function, thinking and behaviour that affect their hopes, dreams, plans and expectations for the future. The whole family system is put under stress when a relative sustains a TBI.

The growing health, social and financial burden of younger people injured in motor vehicle accidents provided the incentive for a partnership between NSW government health and insurance departments to fund and implement a new way of providing health services.

There are now 15 dedicated specialised TBI rehabilitation services for the population of NSW providing a continuum of care involving adult inpatient, paediatric in-reach (sub-acute), transitional living, outpatient and community programs. Rehabilitation intervention extends over time and beyond hospital based care to where the person lives, plays and works.

The BIRP is supported by the Brain Injury Rehabilitation Directorate (BIRD) which is one of 38 clinical networks and institutes of the NSW Agency for Clinical Innovation (ACI). The ACI is a board-governed statutory authority which works with clinicians, consumers and partners to design and drive evidence based innovation to ensure appropriate, effective and sustainable patient centred health care. The underlying principle of the BIRD is to engage health professionals, managers, consumers and the wider community in the process of designing and providing high quality, safe and cost-effective specialised rehabilitation services to meet the recovery, rehabilitation, community integration and social participation needs of children, young people and adults of working age with primarily severe traumatically acquired brain injuries.

The ACI Brain Injury Rehabilitation Directorate aims to lead and coordinate:

- Integrated specialised clinical rehabilitation services
- Improvements in access to services for people with TBI
- Developments in improved treatment coordination resulting in best practice care for recipients of specialised brain injury rehabilitation.
- Engagement of family members and stakeholders in rehabilitation and community outcomes
- Research into and evaluation of BIRP services and outcomes for people with TBI
- Improvements in public awareness and provision of information on brain injury.

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2. About Traumatic Brain Injury

TABLE 1 Determining the Severity of Traumatic Brain Injury

Injury severity category	Initial Glasgow Coma Scale	Duration of Post-Traumatic Amnesia
Mild	12–15	Less than 24 hours
Moderate	9–11	1–7 days
Severe	3–8	1–4 weeks
Very severe	—	More than 4 weeks

Source: Khan et al, 2003

Traumatic brain injury (TBI) is a major public health problem by being the most common cause of death and disability among young people.

The impact of the injury on the brain determines severity and ranges from concussion to persistent vegetative states and is typically classified from mild to very severe, according to the duration of unconsciousness (coma) as measured by the Glasgow Coma Scale and the duration of post traumatic amnesia in hours/days (including any period of unconsciousness) and shown in Table 1. In NSW three commonly used classification tools are used to determine Post Traumatic Amnesia (PTA) duration. These are the Abbreviated Westmead PTA Scale, the Westmead PTA Scale and the Modified Oxford PTA Scale. Measuring PTA is not possible in children under 8 years of age so injury severity is determined by GCS, neuroimaging and the rehabilitation specialist clinical assessment.

Khan et al (2003)[9] analysed Australian data to provide an epidemiological profile of adult TBI as part of their review of brain injury rehabilitation. Some key features of the profile are as follows:

- The incidence of people admitted to hospital for TBI is about 150 per 100,000 populations per year: 12-14/100,000 for severe and moderate and 64-131/100,000 for mild
- In the under 65 year old group the incidence of TBI peaks in the age group 15-35 years
- The ratio of patients aged under 65 years is 3.4 males to 1 female, a differential largely thought to be related to risk-taking behaviour among young males
- Motor vehicle-related trauma accounts for about two-thirds of moderate and severe TBI, with falls and assaults being the next most common causes
- Alcohol is associated with up to half of all cases of people admitted with TBI.
- The prevalence of mild TBI is likely to be an underestimate due to classification and diagnostic errors and because a large proportion of people with mild TBI do not present to hospital.

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Khan et al note that while the introduction of safer car design, random breath tests, compulsory seat belts and other road safety initiatives have decreased the number of overall road fatalities, advances in revival and intensive care have enabled many people to survive injuries that previously would have been fatal. Together with the increase in population, the result is that the number of brain injury adult patients has remained quite stable over time.

In determining the incidence of people in NSW with TBI the ACI Report "ABI service delivery in rural and remote NSW"[10] cites a study that used specific diagnostic codes to record a total of 6,850 adult people admitted to NSW hospitals in 2007 with traumatic brain injury (TBI), and 6,886 total incidences of TBI admissions.

- Of the 6,886 incidences recorded in NSW hospitals, 4,835 were males (70%) and 2,051 (30%) females. Over 5,000 of the total admissions were aged 0-64. Of all TBI incidences, 3.8% were recorded as Indigenous (n=261)
- A total of 897 (13%) had an admission of more than one week, with 5% of this group identified as being Indigenous.

Mitra, B., et al (2007)[11] estimated the incidence of significant head injury in children aged 0-15 years in Victoria over a 2 year period. The incidence was 765 per 100,000 per year. The incidence of admitted head injuries was 75 per 100,000 and the incidence of significant head injury was 7 per 100,000 (or 151 children) per year with 41% requiring surgical intervention. Mortality was 1.6 deaths per 100,000 and all deaths occurred early and were always associated with clinical features of severe head injury.

An incidence based costing approach measured the number of new cases of TBI in the base period (calendar year 2008) and the costs associated with treatment, as well as other financial and non-financial costs (e.g. productivity losses, loss of quality of life) over the person's lifetime, due to TBI.

The total cost of TBI in Australia was estimated to be $8.6 billion, comprising:

- costs attributable to moderate TBI ($3.7 billion) and severe TBI ($4.8 billion)
- financial costs ($3.7 billion) and burden of disease costs ($4.9 billion).

The greatest portion of this cost is borne by individuals (64.9%), the State Government (19.1%) and the Federal Government (11.2%). The lifetime costs per incident case of TBI were estimated to be $2.5 million and $4.8 million for moderate TBI and severe TBI respectively, across Australia.

Laxe et al (2013)[12] in their article explained that the International Classification of Functioning, Disability and Health (ICF) provides clinicians and researchers, disability managers and policymakers and other stakeholders with a comprehensive framework to identify and illustrate relevant domains of human experience that are affected by health conditions such as TBI, in the context of environmental and personal factors.

The ICF Core Sets for TBI are not health status measures but instead are a comprehensive list of domains of functioning that are relevant for TBI and are intended as an international standard of what to measure. However, it also provides a practical checklist for working with people with TBI in the context of specialised brain injury rehabilitation programs in NSW.

TABLE 2 List of 23 categories included in the TBI Brief Core Sets

Body Functions (8)	Body Structures (1)	Activities & Participation (8)	Environmental Factors (6)
• Energy and drive functions • Attention functions • Memory functions • Emotional functions • Higher-level cognitive functions • Control of voluntary movement functions • Sexual functions, • Exercise tolerance functions (includes fatigability).	• Structure of brain	• Carrying out daily routine • Conversation • Walking • Complex interpersonal interactions • Family relationships • Intimate relationships, • Acquiring, keeping and terminating a job • Recreation and leisure	• Products and technology for personal use in daily living • Products and technology for personal indoor and outdoor mobility and transportation • Immediate family • Friends • Social security services, systems and policies • Health services, systems and policies*

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2.1 The consequences of TBI

These can be profound and long-term with personality and behaviour change leading to significant lifestyle effects that flow from neurological and cognitive impairment, as summarised in Table 3.

TABLE 3 Consequences of Traumatic Brain Injury

Neurological impairment (motor, sensory and autonomic)	• Motor function impairment – coordination, balance, walking, hand function, speech • Sensory loss – taste, touch, hearing, vision, smell • Sleep disturbance – insomnia, fatigue • Medical complications – spasticity, post-traumatic epilepsy, hydrocephalus, heterotopic ossification • Sexual dysfunction
Cognitive impairment	• Memory impairment, difficulty with new learning, attention and concentration; reduced speed and flexibility of thought processing; impaired problem-solving skills • Problems in planning, organising, and making decisions • Language problems – dysphasia, problems finding words, and impaired reading and writing skills • Impaired judgment and safety awareness
Personality and behavioural changes	• Impaired social and coping skills, reduced self-esteem • Altered emotional control; poor frustration tolerance and anger management; denial, and self-centredness • Reduced insight, disinhibition, impulsivity • Psychiatric disorders – anxiety, depression, post-traumatic stress disorder, psychosis • Apathy, amotivational states
Common lifestyle consequences	• Unemployment and financial hardship • Inadequate academic achievement • Lack of transportation alternatives • Inadequate recreational opportunities • Difficulties in maintaining interpersonal relationships, marital breakdown • Loss of pre-injury roles; loss of independence

Source: Khan et al, 2003

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In a review of the pertinent issues following paediatric TBI, Savage, et al (2005)[13] identified that professionals and families need to work collaboratively to make a true difference in the lives of children with TBI and there were four major areas for intervention: family, educational, cognitive-communication and behavioural issues.

In addition the authors acknowledge that the needs of the child/young person with traumatic brain injury (TBI), regardless of the severity of the injury are often overlooked and recognition of the long-term consequences is not always central to the management of the child/young person in the school or community. These consequences for children and young people can include:

- Inattention to task; failure to initiate tasks; aggression; destruction; perseveration; inappropriate speech and verbal outbursts; difficulty waiting; age-inappropriate behaviour; inappropriate sexual behaviour; bolting/elopement; non-compliance.

Family members provide emotional, practical and social support and influence rehabilitation and community outcomes. The whole family system is put under stress when a relative sustains a traumatic injury. Families also face many challenges themselves adjusting to the impact of the changes to the person with TBI as well as their own circumstances (e.g., giving up work to be the care giver, changes in sibling and parent relationships). Families remain the constant presence amidst a continually changing spectrum of providers and professionals as treatment and recovery progress. Families share unique roles as: (1) observers throughout all stages of their loved one's care, (2) experts with a dual perspective of pre- and post-knowledge of abilities and difficulties, (3) communicators and liaisons with professional caregivers and (4) advocates for their loved one.

For almost four decades the significant emotional distress experienced by caregivers of persons with TBI has been documented[14] (Sander, M., et al 2013) and more recently, perspectives of adult siblings of people with TBI[15] (Degeneffe & Olney, 2010).

ACI has produced two booklets, There's Always Hope (2006)[16] and Courage to Care (2007)[17] that document the experience of people with TBI and carers in stories, poems and art to benefit and inspire others.

2.2 Understanding complex needs of people with severe TBI in NSW

One of the consistent themes of the literature, and the consultations during this project, is that the specialised rehabilitation interventions provided in the BIRP network are appropriate, relevant and client centred.

The clinical profile and presentation varies widely for each individual. Rehabilitation aims to improve function, reduce activity limitations and participation restrictions using a client centred and goal directed approach.

People requiring specialised brain injury rehabilitation tend to be younger and healthy and require a broader focus to meet ongoing cognitive and psychological needs within the family and social contexts, requiring an integrated continuum of rehabilitation and support, sometimes over many years. The impact crosses all aspects of patients' lives (education, employment, relationships and social integration) and across changing life stages. Understanding clients who have significant and often challenging cognitive and behaviour changes as a consequence of severe TBI is fundamental to specialised brain injury rehabilitation services.

BIRD clinical research projects involving the BIRP network assist in understanding the needs of people with TBI and service systems. The three projects of significance for the Model of Care review are:

ABI service delivery in rural and remote NSW

ACI initiated this project in response to the expressed concerns of the clinical network regarding equitable access for people living in rural and remote areas of NSW and difficulties in the delivery of BIRP services following organisational changes.

This project explored the experiences of consumers and service providers in rural and remote areas (Mitsch et al, 2014).[18] Issues identified included:

- Living remotely from a BIRP will limit access to specialised ABI rehabilitation at the level of intensity and type required. Transport issues and inadequate support for families of the person with the ABI create additional barriers
- Aboriginal people have specific additional cultural needs and issues related to kinship, gender and shame. The development of trust and engagement with an Aboriginal community is difficult when practitioners within the rural BIRP are not based within that town/community
- Some areas do not receive a specialist ABI rehabilitation service, or the BIRP service provided is limited due to distance and workforce. Paediatric brain injury rehabilitation services are primarily located in metropolitan NSW with limited specialist support in rural and remote NSW

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- Variation in skills, knowledge and the numbers of staff within rural BIRPs has an impact on the provision of brain injury rehabilitation in remote areas. The limited skills, knowledge of ABI and availability of staff within non-brain injury organisations have a further impact on a lack of service equity in rural and remote NSW
- People who live in remote areas of NSW typically do not have access to a community rehabilitation model of service provision and to services that understand ABI and the needs of the person returning home following acute care.

Key principles and recommendations were developed to address these issues. However, implementation of the recommendations has been limited. ADHC was a key partner in this project with a plan to use ADHC resources to create a presence in rural and remote communities. The restructure of ADHC and commencement of the National Disability Insurance Scheme (NDIS) trials meant that the implementation plan was no longer feasible. The reorganisation of LHDs meant that recommendations for service changes, particularly in Western and Far Western LHDs did not occur.

The Adult and Paediatric Challenging Behaviours Project[19]

This project found that:

- Challenging behaviours for community-dwelling adults with severe TBI were widespread, having an overall prevalence rate of 54% - with inappropriate social behaviour, verbal aggression and adynamia being the most common. Over one-third of the adult study sample displayed more than one type of challenging behaviour
- Adults with pre-existing mental health or drug and alcohol issues were more likely to exhibit challenging behaviour following a TBI. In addition, because of their brain injury, people had difficulties accessing non-acute services to manage comorbidities once discharged home
- 51% of 8-18 year olds who were active clients of the paediatric BIRPs and living in the community met criteria for challenging behaviour. While the most prevalent challenging behaviours were the same as for adults (inappropriate social behaviour, verbal aggression and adynamia) the prevalence across all the remaining categories was different.

A number of principles and recommendations for change were identified to improve management and clinical practices for adults and children with TBI and challenging behaviour. Although ACI worked in collaboration with ADHC and LTCSA to design a solution for those with the most challenging behaviours, this was not supported, funded and implemented. The challenge remains for how to build into the BIRP Model of Care the identified best practice recommendations to improve the lives of people with challenging behaviour after severe TBI.

The investigation of Vocational Programs and Outcomes for people with TBI in NSW[20]

Return to work (RTW) and participation in employment is an international marker of rehabilitation outcome following a health event. In recognition of the cognitive, psychosocial and behavioural consequences of TBI, a collaborative project between ACI and the Lifetime Care and Support Authority (LTCSA) was established in 2012. 721 people who sustained a TBI as an adult and were active BIRP community clients participated.

It was found that employment rates differed across the 11 BIRP regions, ranging from 16.7% to 42.9% (average 29%) and there was a marked post injury shift from full-time to part-time employment. According to the literature review in the Report, this average is considered to be low. The best outcomes were associated with return to pre-injury employment.

Factors found to contribute to poor employment outcomes include the severity of TBI, pre-injury work and educational background, post-injury psychosocial issues (including substance abuse, emotional disturbance and challenging behaviours), limited job options and transport barriers.

To improve RTW outcomes BIRD will implement a new way of working that engages health, vocational rehabilitation and employment services aimed at increasing the NSW average from 29% to at least the international average (approximately 35%) or better, as a consistent standard.

ACI has a partnership with NSW Government Safety, Return to Work and Support to plan and implement the Vocational Intervention Program in three NSW regions as the first step in providing two models of work options for people with TBI that can be sustainable within the NSW and Commonwealth employment contexts.

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3. Developing a Model of Care

A “Model of Care” broadly defines the way health services are delivered and the way in which a patient travels through the system. It outlines best practice care and services for a person, population group or patient cohort as they progress through the stages of a condition, injury or event. It aims to ensure people get the right care, at the right time, by the right team and in the right place.[21]

ACI accepted the clinical network recommendation that it is timely to review and update the BIRP Model of Care for NSW because:

- BIRD has completed clinical research projects across the network that have provided an increased understanding of the needs of people with TBI and options for best practice service delivery
- There has not been a comprehensive review since the BIRP was established and during this time there have been significant changes in governance, health structures, funding and insurer arrangements. Although BIRP services were included in the review and recommendations of the Greater Metropolitan Transition Taskforce, the rural and paediatric services were out of scope
- A BIRP Model of Care review provides an opportunity to improve equity of access and best practice service delivery for all people with severe TBI in NSW
- BIRP clients and services were excluded from the development of the NSW Rehabilitation Model of Care that is currently being implemented state-wide. The interface between these 2 models now needs to be explored
- BIRP governance systems and funding arrangements have changed over time, leaving disjointed governance and financial management across the health service system
- Insurer stakeholders have changed leading to altered incentives, workload and priorities
- The interface between the current part funding model, budget allocations and the application of Activity Based Funding (ABF) for specialist sub-acute programs is unknown

In developing a Model of Care, the ACI uses the redesign methodology, a project management methodology comprising five stages, as depicted in Figure 1.

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FIGURE 1 Process Flow Chart for Developing a Model of Care (MOC)

Project Initiation

Identify an area of need, build a case for change and obtain sponsorship to proceed with the program of work

Issue or opportunity arises:

- Clinician/ACI Network/Consumer identified innovation
- Unwarranted clinical variation
- Priority area (Minister/DG/ LHD/CEC)
- Out of date MOC

Create the initial high level 'case for change' - quantify the extent of the issue and the cost of continuing business as usual

Develop and agree project aim, objectives and scope

Generate Sponsorship

- ACI executive sponsorship/ prioritisation for the program of work
- Seek direction from LHD clinicians, managers and stakeholders - is this a piece of work they will value?

Diagnostic

Define the problem - understand the root cause to treat the real problem and not just the symptoms.

Define the problem using a variety of tools:

- Consultation such as workshops, interviews and brain storming
- 'As is' analysis - what does it look like now?
- Data review including demand analysis, epidemiology and service utilisation.
- Financial analysis of the cost of continuing business as usual
- Review literature and analyse any innovation already in this field

Finalise case for change

Identification and prioritisation of issues

Revisit aims and objectives to ensure project is on track

Solution Design

Develop and select solutions. Create and document the MOC

Develop a vision for what services should look like

Develop a range of solutions that address the problems defined in the diagnostic

Test these solutions widely including economic appraisal and/or piloting to select the most appropriate solution

Develop evaluation framework

Develop and document the MOC

Seek endorsement of the MOC from appropriate stakeholders

Plan for disinvestment - what older models or technologies will no longer occur as a result of the new model?

Implementation

Support the health system to execute the changes needed to implement the MOC

Define the change clearly

Develop business case

Assist LHDs to conduct a self assessment/gap analysis

Seek endorsement of the business case/ resourcing strategy

Generate local executive sponsorship and create a governance structure

Build the capability of front line clinicians and managers to change the process/system

Develop a Communication plan and identify risks to implementation

Develop reinforcement strategies for LHDs

Sustainability

Optimise use of the MOC, monitor the results and evaluate the impact

Ongoing monitoring and local accountability

Review the impact of the MOC and adjust practices to optimise use

Ensure disinvestment occurs

Final evaluation of economic and clinical outcomes

Knowledge Management "sharing our lessons"

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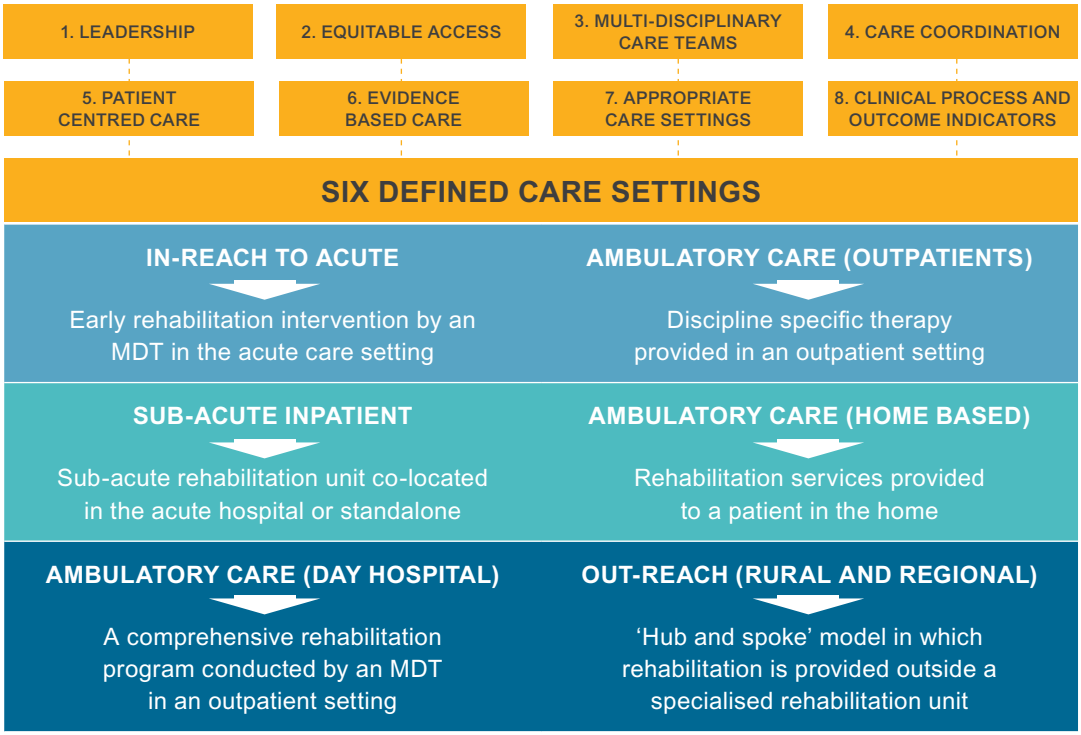
FIGURE 2 NSW Rehabilitation Model of Care



This report documents the diagnostic phase of the project and will provide input for the solution design phase. This diagnostic report will outline the current state, issues and root causes to build the case for change.

This process was used in developing the NSW Rehabilitation Model of Care. This defined six settings in which rehabilitation occurs and eight principles of care.

Whilst the model provides strategic direction, it allows flexibility for local services to be designed to meet local needs, leaving room for innovation in service delivery.

The NSW Rehabilitation Model of Care is currently in implementation phase and has a focus on adult general rehabilitation services and the primary rehabilitation impairments considered were stroke, orthopaedic, re-conditioning impairment and high impact areas (such as amputees). Specialised rehabilitation programs including the BIRP for people with traumatic brain injury were specifically excluded from this review.

In developing the NSW Rehabilitation Model of Care there was recognition of the need for a diverse range of health professionals, services and external agencies to work together to overcome system challenges such as funding, administration and reporting structures with the aim of achieving equity of access, appropriateness of care and consistency in service quality. A number of the identified recommendations aim to broaden the rehabilitation approach to provide more cognitive and psychosocial rehabilitation services and improve the client centred approach. Many of these elements already exist within the BIRP model of specialised rehabilitation and are integral to the underlying principles of the clinical network.

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Implementation of the NSW Rehabilitation Model of Care will necessitate that LHDs review the provision of rehabilitation services and to undertake a gap analysis of the 'as is' rehabilitation practice when compared to the NSW Rehabilitation Model of Care. Although out of scope for the development of the rehabilitation Model of Care there is now a need to ensure that the model of specialised rehabilitation for people with traumatic brain injury (adults, young people and children) interfaces with the NSW Rehabilitation Model of Care currently being implemented in LHDs across NSW.

The outcomes of this diagnostic project will be examined against the principles and care settings outlined in the Rehabilitation Model of Care to identify how much synergy there is between the models, and where TBI needs additional elements.

3.1 Project Methods

This diagnostic project will inform any organisational and service delivery changes for the BIRP Model of Care in the future. The project was able to:

- Review the Models of Care for specialised brain injury rehabilitation in Australia and internationally, to ensure that the BIRP model as it is being delivered across NSW to the patient cohort and their carer/ families continues to meet evidence based best practice standards
- Identify key documents and reports that contributed to the establishment and operation of the BIRP Model of Care
- Provide a summary of the current funding system(s) for BIRP services and the impact of Activity Based Funding (ABF) on the delivery of services
- Identify key themes and issues that will guide decision making for the BIRP Model of Care to ensure that the organisational and service delivery framework addresses the specialised rehabilitation needs of people with TBI.

The project has involved:

- A review of the national and international literature on Models of Care for brain injury rehabilitation (see appendix F)
- Development of a survey sent to all of the BIRP services across NSW (appendix D) for the purpose of gathering initial preliminary information
- Site visits and consultations with each of the BIRP services (appendix C) to build on the survey responses and gather further information
- A series of consultations with key stakeholders including patients and their families or carers, the Ministry of Health, other NSW government agencies, consumer organisations and non-government service providers (see appendix B for a list of stakeholders consulted)
- A workshop with LHD representatives (including, but not restricted to, BIRP service representatives) on 8 April 2014 to discuss a discussion paper on the diagnostic project (see appendix J for a list of the workshop participants)
- Identifying and including key documents and reports that contributed to the establishment and operation of the BIRP Model of Care.

This project has been oversighted by a steering committee (see appendix A for a list of the steering committee members) who provided input to the project methods discussed in a draft report. This final report incorporates their feedback.

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The project's scope includes:

- Evidence base for TBI rehabilitation interventions
- Evidence base for organisation of specialist TBI services including the equity of access for delivery of specialist services in rural and remote communities and the additional needs of Aboriginal people
- Benchmarking the model with an interstate and international evidence base for acquired (traumatic) brain injury and with the NSW Rehabilitation Model of Care
- Referral pathways:
  - Trauma centre and acute hospital referral pathways
  - Use of Post Traumatic Amnesia (PTA) assessment for deciding treatment pathways for patients admitted to BIRP/not admitted to BIRP from Trauma Centre and acute hospitals
  - BIRP Pathways for admitted and discharged patients for inpatient, transitional and community settings of care
- People admitted to BIRP services who do not meet admission criteria (e.g., less severe TBI, non TBI and age)
- Funding models: current budgets and utilisation of current insurer income, impact of ABF, future demand and resource allocation
- Paediatric BIRP Services: Gaps have been identified within the network that compromise best practice service delivery for the operation of outpatient therapy services and limited access to specialist paediatric TBI rehabilitation services, particularly for non-metropolitan areas of NSW. There is one dedicated team in rural NSW and some rural adult BIRPs have co-located coordinator/case manager positions primarily involved in the return to home and school. Paediatric services was out of scope for model development with the NSW Rehabilitation Model of Care currently being implemented in NSW
- How LHDs with adult and/or paediatric clients with TBI manage the needs of their population when accessing services in other LHDs
- Access to Mental Health/ Drug and alcohol non-acute services to support clinical management of BIRP clients
- Management of people with challenging behaviour admitted to BIRP services
- Discharge pathways for inpatients and timely access to community support services for rehabilitation and social participation
- The acute care pathway for severe TBI is primarily into specialised rehabilitation (BIRP services) with admission criteria available and known. However, the pathway and process for decision making for people with non-traumatic ABI admitted to BIRP is not clear. The referrer pathways and determinants for admission (e.g., resource availability, local response, age, severity, presence of complex psychosocial factors, cognitive and behaviour management issues) will be explored to assist in understanding the needs of this group.

Out of scope are:

- Review of the BIRP admission criteria
- Patients not admitted to BIRP services with non-traumatic ABI (including young strokes, brain tumours, drug and alcohol related brain impairment, infections etc.)
- Support for young adults transitioning to work
- People with TBI entering or leaving Justice Health or corrective services
- Roadside retrieval processes
- NSW Ambulance Service

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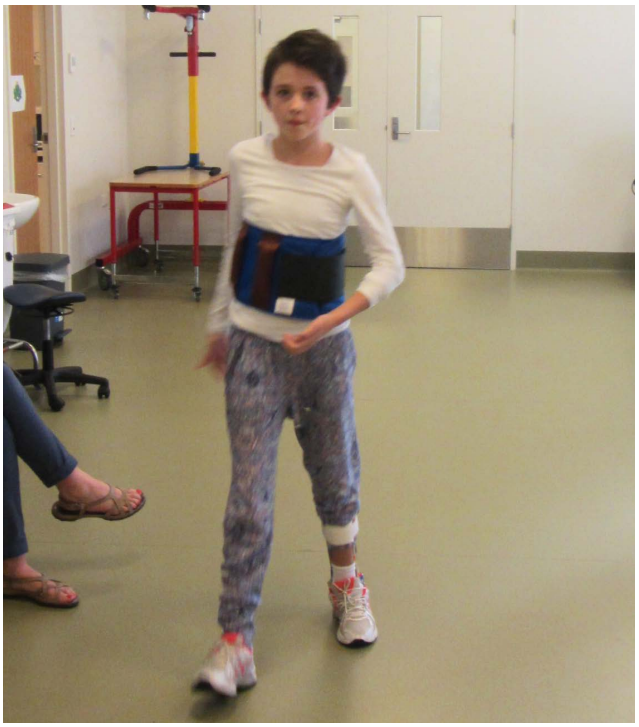
4. Models of brain injury rehabilitation

In the literature review (appendix F) models of brain injury rehabilitation are promoted that have the following key features:

- Early engagement of rehabilitation services to facilitate recovery and minimise the impact of the injury
- Specialist sub-acute brain injury rehabilitation beds and in-reach services
- Early referral and communication between acute hospital settings and the specialist units
- Community-based rehabilitation
- Extended engagement with children and families to manage developmental milestones

The BIRP Model of Care includes these key features and is integrated within a whole of state network of health services for retrieval, trauma, hospital admission, acute and sub-acute care and commencement of specialised TBI rehabilitation interventions that extends into the community and can be required for long periods of time. The model is decentralised with metropolitan and rural locations, promotes a social rehabilitation model that is contextually based and occurring as close as possible to where the person lives.



4.1 Literature Review

To inform the diagnostic report, a literature review on brain injury rehabilitation Models of Care in other jurisdictions in Australia and internationally was undertaken. The literature review, attached in appendix F, faced a number of challenges:

- Time and resource constraints precluded a comprehensive search of the grey literature, in particular
- Much of the literature focuses on ABI rather than specifically on TBI
- The terms ‘Model of Care’ and ‘clinical pathways’ have different connotations in different settings
- Moreover, detailed information on Models of Care was limited with many sources simply describing the service events as opposed to a complete system.

Nevertheless, the literature review did identify a number of common strands that are pertinent to the provision of the Model of Care in NSW. Firstly, many services are founded on a set of common principles including:

- Client centred care
- Goal-oriented approaches
- multi-disciplinary team approach
- Policies and procedures to guide service delivery (e.g. referrals, discharge etc.)
- Quality improvement including strategies to improve services, engage consumers and manage risk
- Facilities and equipment – appropriateness of the physical environment and access to equipment/ aides to assist with rehabilitation
- Access to and participation in education and research
- Data reporting and management - to measure outcomes and inform service planning and delivery.

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Most services are also premised on a spectrum or continuum of services encompassing:

- Early recognition of brain injury during emergency and acute management
- Early and specialist rehabilitation
- Community-based rehabilitation, including day centres, outpatients, transitional centres, out-reach with an emphasis on facilitating patients' return to their home
- Vocational rehabilitation
- Personal care and support services
- Follow-up and re-entry, when required.

Over time, the focus of rehabilitation tends to shift from clinical issues and extended activities of daily living to community-based interventions that aim to improve quality of life and psychological adjustment.

A common theme of the literature is that good patient outcomes are facilitated by active engagement with families and carers and coordinated, specialist interdisciplinary care involving a range of health professionals. The literature also suggests there be effective coordination between the health and community service sectors in meeting the complex interaction of health, social and quality of life needs for people with brain injury. However, the issue of poor coordination between these settings is noted in some studies.

4.2 The NSW experience: historical perspective

The design process used in the early 1990's to establish the NSW Brain Injury Rehabilitation Program (BIRP) has similar elements to the ACI redesign methodology outlined in Figure 1 although referred to as a program rather than explicitly described as a Model of Care.

Traumatic brain injury (TBI) was becoming the most common cause of death and disability among young people with rising health, social and insurance costs being the trigger to initiate committees, working groups, consultations and projects for the diagnostic and solution design stages (The Cuff Report). Implementation planning was via a submission process with each health region being required to submit a proposal for service provision and a funding strategy to ensure that the program and principles met local needs and was available to all people in NSW with severe TBI. Geography, population, incidence of brain injury and other available services needed to be considered when developing submissions to ensure access to the right service at the right time for the target population in NSW. The staged implementation process was overseen by a Joint Management Committee, chaired by the (then) Department of Health and including a representative of the Brain Injury Association of NSW. Key features of the program included adult and paediatric services; metropolitan and rural centres to cover all of NSW with hospital and community-based settings of care depending on location and the services being provided.

Key meeting minutes, documents and reports provide important information for the various activities involved for establishment and operation of BIRP services. However, unlike the current ACI redesign methodology there is no single document or report that summarises the Model of Care and makes this information available for those not directly involved in the service network.

A number of project reviews and research were commissioned by NSW Health and the Motor Accident Authority of NSW to establish and review BIRP service models. As an example, the Australian Council of Health Standards (1992)[22] was project funded to develop a quality framework for establishing service models. Individual BIRPs were provided with 13 core standards and engaged in an accreditation process to ensure that the establishment and initial operation of BIRP services was consistent with the program principles. Bosi[23] organised a consensus process to agree on a set of 10 core principles and 5 enabling principles for the state-wide clinical network.

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In April 1999 the Brain Injury Rehabilitation Speciality Services Plan Discussion Paper[24] was released providing a summary review of progress and funding.

One of the unique features of BIRP services is the establishment of metropolitan and rural services. In 2004 Harradine, P.G., et al[25] completed a 2-year multicentre study of an adult BIRP cohort with follow-up at 18 months after injury. Functional, psychosocial, emotional and vocational outcomes were documented. The results were similar for both rural and urban groups for demographic details, injury severity, lengths of stay in intensive and acute care wards. There were no significant group differences in functional outcomes, including return to work, at follow-up.

The conclusions from these findings contrasted with previous research that has reported poorer outcomes after TBI for rural residents, and suggest that the integrated network of inpatient, outpatient and out-reach services provided throughout NSW through the BIRP network provides effective rehabilitation for people with severe TBI regardless of where they live.

In June 2001, the Greater Metropolitan Services Implementation Group released a report[26] identifying 162 recommendations relating to a broad range of health services in greater metropolitan Sydney hospitals. The report recommended that

- NSW BIRP units maintain their role in meeting the behavioural, cognitive and psychosocial needs of people with severe TBI
- That a regional brain injury rehabilitation service have reasonable access to all of the following components:
  - specialist medical inpatient care
  - community rehabilitation programs
  - transitional living programs
  - services dedicated for children and adolescents
  - community development approach with family and carer support
  - quality improvement programs
  - education program, research and professional development
  - appropriate data collection.

In addition to those listed, others included

- Maintain an adult inpatient bed capacity of 48 beds for NSW with a planned review
- strengthen the linkages between metropolitan and rural BIRPs
- Adopt a best practice model of rehabilitation for children and adolescents who have sustained ABI in NSW
- Continue to admit selected individuals with complex needs and non-traumatic brain injury subject to availability of resources, lack of alternative appropriate services and at the discretion of unit directors
- Develop a data strategy for state-wide clinical and service reporting.

As a direct outcome of this report recurrent funding was provided to ACI (then GMCT) and LHDs (then Area Health Services) in the Greater Metropolitan Sydney area to assist in the implementation of the recommendations. In 2002 clinical governance transferred from NSW Health to ACI (then GMCT) for the BIRP and ACI established the Brain Injury Rehabilitation Directorate as the state-wide clinical network. ACI continues to recurrently fund the Brain Injury Rehabilitation Directorate for state-wide clinical networking. Funding governance of the specialty service did not transfer as part of this clinical restructure but was retained by NSW Health.

The current BIRP Model of Care review is an opportunity to review the specialised model of brain injury rehabilitation using the ACI redesign methodology.

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5. The NSW model of specialised brain injury rehabilitation

A specific specialised Model of Care for people with severe brain injury from trauma has been operational in the public health system for over 21 years and is known as the NSW Brain Injury Rehabilitation Program (BIRP). This section provides a current BIRP overview including principles, organisation of services and staff.

5.1 NSW Brain Injury Rehabilitation Program (BIRP) Principles

The BIRP service philosophy can be characterised as a social rehabilitation approach underpinned by a number of principles documented in the establishment phase and which have been expanded over time. A number of these principles were discussed at the April 2014 workshop and are included in Appendix K.

5.2 NSW Brain Injury Rehabilitation Program service configuration

NSW has seven NSW Brain Injury Rehabilitation Programs (BIRPs) located in Sydney and Newcastle metropolitan areas with eight BIRPs in key regional centres (Figure 3).

A review of access to the specialist brain injury rehabilitation services by population across the greater metropolitan area was undertaken in 2004.[27]

The 15 BIRPs are located in specific Local Health Districts (LHDs) and operate for defined areas of NSW and ACT relevant to the type of program being provided. Table 4 provides a summary of BIRP services, the LHD in which they are located and the programs being provided. LHDs provide governance and financial management for the BIRPs located in their district and do not separately report on program outcomes to the Ministry of Health.

The three adult inpatient services and the three paediatric in-reach services cover about a third of the state each. Table 5 provides the Greater Sydney and NSW catchment areas of the metropolitan adult inpatient and paediatric in-reach BIRP services. Access to BIRP services and intensity of intervention can be limited by distance and travel time in some areas of NSW, particularly for rural and remote locations.

Some clients will transition from paediatric to adult services upon completion of secondary education, when moving towards improving independence or introducing vocational goals.

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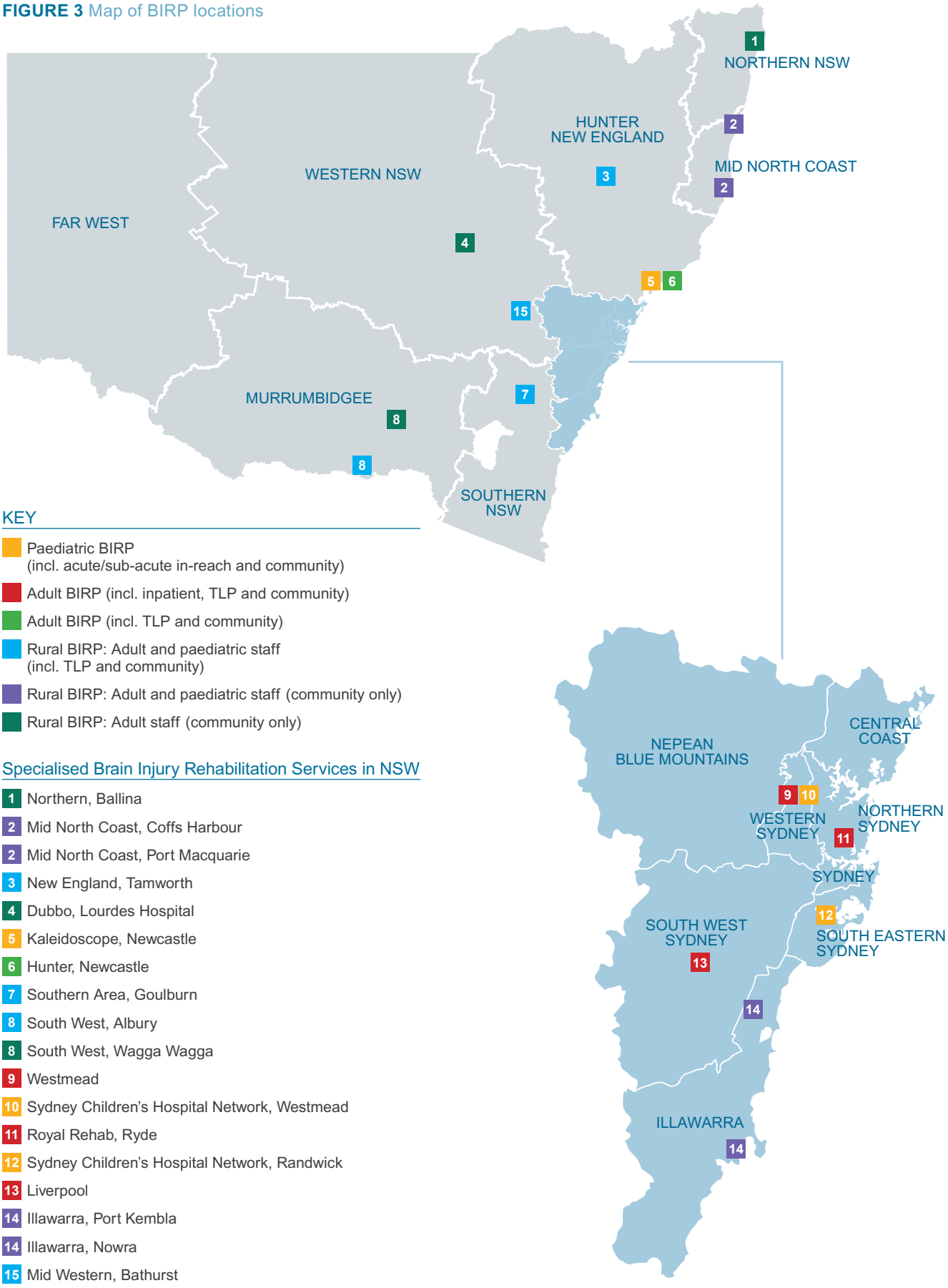
FIGURE 3 Map of BIRP locations



KEY

- Paediatric BIRP (incl. acute/sub-acute in-reach and community)
- Adult BIRP (incl. inpatient, TLP and community)
- Adult BIRP (incl. TLP and community)
- Rural BIRP: Adult and paediatric staff (incl. TLP and community)
- Rural BIRP: Adult and paediatric staff (community only)
- Rural BIRP: Adult staff (community only)

Specialised Brain Injury Rehabilitation Services in NSW

1. Northern, Ballina
2. Mid North Coast, Coffs Harbour
2. Mid North Coast, Port Macquarie
3. New England, Tamworth
4. Dubbo, Lourdes Hospital
5. Kaleidoscope, Newcastle
6. Hunter, Newcastle
7. Southern Area, Goulburn
8. South West, Albury
8. South West, Wagga Wagga
9. Westmead
10. Sydney Children's Hospital Network, Westmead
11. Royal Rehab, Ryde
12. Sydney Children's Hospital Network, Randwick
13. Liverpool
14. Illawarra, Port Kembla
14. Illawarra, Nowra
15. Mid Western, Bathurst

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TABLE 4 BIRP programs and LHD

NAME	LHD	Adult Inpatient	Transitional Living Program	Adult Community team	Adult Case Manager	Paediatric In-reach to acute	Paediatric Community team	Paediatric case manager
Westmead BIRS	Western Sydney LHD	√	√	√				
Liverpool BIRU	South Western Sydney LHD	√	√	√				
BIRS Royal Rehab	Northern Sydney LHD	√	√	√				
South West BIRS	Murrumbidgee LHD		√	√			√	
Northern BIRS	Northern NSW LHD				√			
Hunter BI Service	Hunter New England LHD		√	√				
New England BIRS			√	√				√
Kaleidoscope PBIRT						√	√	
Mid North Coast BIRS	Mid North Coast LHD			√				√
Dubbo BIRP Lourdes Hospital	Western NSW LHD				√			
Mid-Western BIRP Bathurst Hospital			√	√				√
Southern Area BIS	Southern NSW LHD		√	√				√
Illawarra BIS	Illawarra Shoalhaven LHD			√				√
BIRP, Rehab2Kids Sydney Children's Hospital Randwick	Sydney Children's Hospital Network LHD					√	√	
BIRS, Kids Rehab, The Children's Hospital Westmead						√	√	

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TABLE 5 BIRP Adult and paediatric sub-acute catchment areas for NSW

BIRP adult Inpatient service	Greater Sydney catchment	NSW catchment
Liverpool BIRU	SWSLHD, southern sector SLHD and SESLHD	Illawarra Shoalhaven LHD, Murrumbidgee LHD, Southern LHD plus ACT
Royal Rehab BIRS	NSLHD; CCLHD, northern sector SLHD and SESLHD	Hunter New England LHD, Mid North Coast and Northern LHDs
Westmead BIRS	SWLHD, Nepean Blue Mountains LHD	Western NSW LHD, Far West LHD
BIRP Paediatric In-reach services*		
PBIRT Kaleidoscope JHH Newcastle	CCLHD	Hunter New England LHD, Mid North Coast and Northern LHDs
BIRP, Rehab2Kids Sydney Children's Hospital Randwick	SWSLHD, SLHD, NSLHD and SESLHD	Illawarra Shoalhaven LHD, Murrumbidgee LHD, Southern LHD
BIRS, Kids Rehab, The Children's Hospital Westmead	SWLHD, Nepean Blue Mountains LHD	Western NSW LHD, Far West LHD

* Paediatric retrieval pathways usually determine the ongoing engagement of the Paediatric BIRP co-located with the initial treating hospital. The metropolitan Paediatric BIRPs will continue to provide community-based rehabilitation for clients and families in the absence of specialist paediatric case managers or clinical teams closer to where the child/family lives. Travel time and use of IT is therefore as significant a factor for paediatric services as it is for rural services.

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5.3 NSW Brain Injury Rehabilitation Program models of service delivery

5.3.1 Network of BIRP Adult services

Adult BIRPs provide services for clients fulfilling the following primary criteria:

- The client has suffered a moderate to extremely severe TBI
- The client is aged 16-65 years
- The client or significant other/s lives in the area covered by the BIRP or, particularly for adult inpatient services, area of the state covered by each metropolitan BIRP.

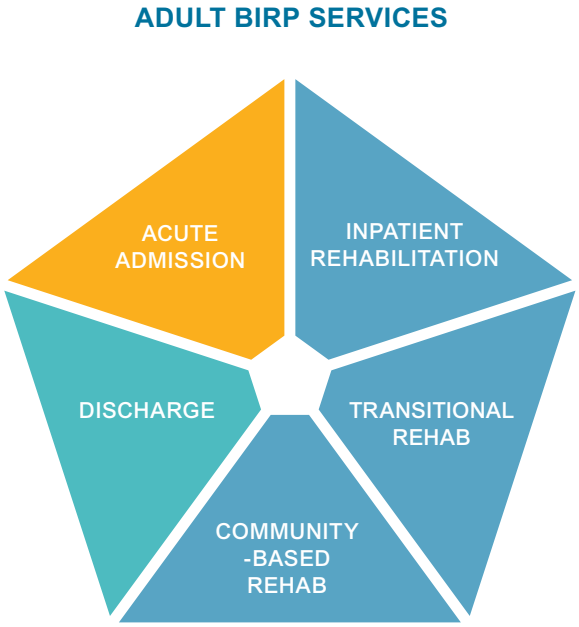
People referred with complex mild TBI or brain injury from other causes (e.g. stroke) are admitted on an individual basis in consideration of client need, access to alternative options and resource availability.

Figure 4 depicts the core components in the continuum of services for the adult BIRP network of services. It does not reflect the multiple entry and exit points in and out of BIRP services or the continual and intermittent nature of the rehabilitation process. For example, some patients may not require transfer to an inpatient BIRP unit or may transition from community to inpatient settings and others will be discharged and readmitted in response to changing needs.

The core components from Figure 4 are described below:

- Three dedicated **inpatient wards** for specialist rehabilitation for adults who are medically stable and requiring a high level of care, have had a severe or very severe TBI and may still be in a state of confusion (post traumatic amnesia). The units operate 24/7 with doctors, nurses, allied health and support staff in the team. The majority of admissions are received from trauma hospitals. Each metropolitan unit accepts people living in other LHDs in need of this level of inpatient hospital based specialist rehabilitation

FIGURE 4 BIRP Adult Network of Services



- **Transitional Living Programs (TLPs)** provide contextually based rehabilitation with a community reintegration and social participation focus. TLPs emphasise a client centred goal planning approach to rehabilitation within a supported therapeutic environment. Intervention is provided in individual and group sessions that incorporates functional skills as well as more complex training in understanding the impact of brain injury, social communication, memory and even managing behaviour changes that affect performance in different situations. Involved staff provide formal and informal support and feedback about performance. The person is able to learn useful strategies to manage impairments arising from brain injury and apply these skills in home, education, employment and community settings. Family members and carers are engaged in the rehabilitation process to maximise opportunities to support clients to translate skills into daily living.

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Most clients are admitted as a continuum of care (in the same BIRP or as a transfer of care from metropolitan to rural BIRP services) or further down the track in response to changing needs for assessment and rehabilitation to support community participation goals. There are dedicated staff and most TLPs operate on a Monday to Friday basis thereby enabling the person to reconnect with their social network, practice and improve skills in everyday situations, identify barriers to participation and develop new and personally relevant goals.

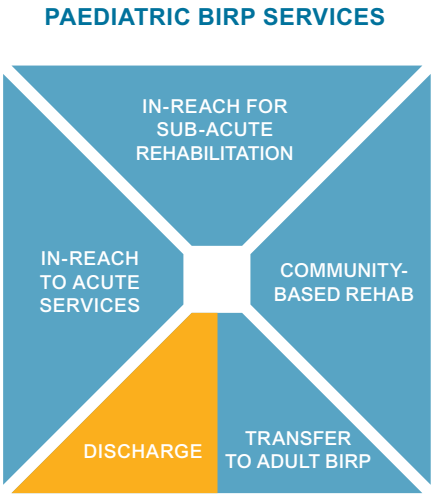
Service delivery and operation details are provided in the ACI (then GMCT) review of Transitional Living Programs in the NSW BIRP Report: Stage One (2005)[28] and Stage Two Report (2006)[29].

Evaluation of client outcomes commenced in 2007 with the introduction of two standardised measures of outcome. Analysis is used in service planning for improving service delivery across the TLP service network.

- **Community-based rehabilitation** that provides contextually based therapy and case management services. Outpatient medical and multi-disciplinary clinics are provided in metropolitan and some rural areas

Case management is integral to the specialist rehabilitation team. Two rural BIRPs provide specialised BIRP case management services only. These BIRPs rely on consultation services to access medical and therapy services for outpatient clinics and the ability to refer clients to a range of other public and private medical and allied health staff, health and community services.

FIGURE 5 BIRP Paediatric Network of Services



5.3.2 Network of BIRP Paediatric services

Figure 5 represents the core components of the BIRP paediatric network of services. It does not reflect the continuous and intermittent service involvement that occurs across both developmental and educational life stages.

The core components of the network of BIRP Paediatric services consist of:

- **In-reach and sub-acute specialised brain injury rehabilitation services** – Early notification facilitates the provision of specialised rehabilitation to children with an acquired brain injury (traumatic and non-traumatic) admitted to acute care beds in the 3 metropolitan paediatric trauma hospitals in NSW. There are no dedicated paediatric inpatient sub-acute rehabilitation beds
- **Community-based rehabilitation** where therapy is delivered and practiced in everyday environments within the child's home, school and community

Outpatient medical and multi-disciplinary clinics are provided in metropolitan and some rural areas.

Case management is integral to the specialist paediatric rehabilitation team. Rural Paediatric BIRP case managers are co-located with 5 adult rural BIRPs for specialist rehabilitation case management services.

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5.4 NSW Brain Injury Rehabilitation Program Staffing

The staged implementation of the BIRP occurred over a number of years in different health districts to fund different program elements based on population and capacity to support a specialist rehabilitation program. Although this has resulted in staffing differences and variation in the service types being delivered a positive factor is the level of staff retention in key positions across the network.

In the diagnostic project, it was recognised that when quarantined funds were abolished inconsistencies in the allocation of budgets and management of revenue developed. These continue to impact on staffing levels, the range of clinical services being delivered and capacity to respond to new initiatives for working with people with TBI.

Staffing needs change at different time points during recovery, rehabilitation and community integration. The initial period post injury has a high profile for medical and nursing services. Early rehabilitation is about recovery and reducing activity limitation while further down the track the focus is independent living, community and social participation.

Staffing variations occur in a number of key clinical areas across the network of BIRP services:

- The overall number of staff available for each program type, the classification of staff and their roles when recruited to work in specific positions
- The way in which staff is organised also varies, particularly relating to direct employment (full time, part time and casual), consultancy or brokered services
- There may also be variability in the roles of staff in the different services/programs because the client is in a different stage of recovery and rehabilitation e.g., speech pathologist in acute care/adult inpatient ward does frequent swallowing assessments whereas a community speech pathologist is more involved with language and social communication skills

Best practice models of specialised brain injury rehabilitation are multi-disciplinary and client directed to respond to the medical, communication, physical, cognitive and psychological impairments of BIRP clients following a significant health event.

The range of staff recruited to therapy teams includes social workers, psychologists (including neuropsychology and clinical psychology), physiotherapists, medical doctors, nurses, occupational therapists, speech pathologists, recreation officers, living skills educators, music and play therapists, dieticians, teachers, exercise physiologists, school and vocational counsellors and therapy support staff. In the BIRP, case management is a specialist role in the rehabilitation team with BIRP Case Managers working directly with clients and families. The team includes managers, educators and other staff with non-clinical roles (e.g., administrative services).

Attracting and retaining experienced clinicians to maintain specialised brain injury rehabilitation knowledge and the multi-disciplinary team structure is an important factor for ensuring that the right service is available at the right time to meet the needs of clients and families.

The Australian Faculty of Rehabilitation Medicine (AFRM) Standards 2005 provided staff establishment data for adult rehabilitation medicine services in public and private hospitals. However, this relates to neurological rehabilitation and acknowledges that there will be differences for specialised rehabilitation programs for brain injury and spinal cord injury.

AFRM does not provide staffing standards for paediatric ABI rehabilitation services; adult residential (admitted or non-admitted) transitional rehabilitation programs or non-admitted ambulatory or out-reach rehabilitation.

Staffing standards that accurately reflect the multi-disciplinary rehabilitation approach and the nature of work with people with complex needs across all settings of care would be useful in health workforce planning and establishing the right price for the right service in Activity Based Funding model development. The current review process being conducted by the AFRM may provide useful information when completed.

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6. Using data to understand people with severe TBI in NSW

The peak incidence in Australia of TBI in those under 65 years of age is in healthy young males from road accidents, with a male to female ratio of 3:1. About 40% of survivors of TBI are in the 15-25 year old age range but form only 15% of the Australian population. Almost 40% of TBI in children under 5 years of age is caused by a fall or non-accidental injury. An incidence peak occurring after 75 years of age is caused from falls.

One of the challenges for this diagnostic project was the difficulty of obtaining NSW data that follows the client from before admission to BIRP services and after discharge.

Nevertheless, the project was able to draw on the following data sources in providing a snapshot of clients with severe brain injury.

- The BIRD Annual Report of BIRP Activity
- An initial report of hospital data prepared by the Health Economics and Evaluation Team in February 2014 and updated in July 2014 (the HEET report)
- A profile of participants in the Lifetime Care and Support Scheme (LTCS) as at 31 December 2013, from the online LTCS newsletter
- Inpatient adult summary data from the AROC benchmarking workshop held in November 2013, as the public report is not available. AROC is the Australian Rehabilitation Outcomes Centre (AROC); a joint initiative of providers, funders, regulators and consumers from the rehabilitation sector.

6.1 Clients admitted to BIRP services

Data is entered at each of the 15 BIRPs and collected for analysis and preparation of the BIRD Annual Report of BIRP Activity by BIRD staff, with oversight from the Data and Information Management steering committee.

Client data is currently only collected, analysed and reported for the episode of care between admission and discharge from BIRP services. Data collection ceases for clients following discharge from BIRP services unless a new episode of care in a BIRP service commences. Intermittent data collection post discharge can occur for various projects and research activities locally and as a component of the BIRD network workplan.

The BIRD Annual Report provides BIRP activity including information on trends, client demographic and injury data, referrals, admissions and discharges, total clients, program duration and compensation data.

Overall, the total client intake has been relatively steady over the past seven years, ranging from 1,000 to approximately 1,100 per annum in NSW. However, collecting and reporting quality trend data on BIRP service utilisation and patient outcomes is difficult and this is a function of a number of factors:

- The decentralised nature of BIRP service provision such that multiple entities under separate governance are involved in the program
- The complexity of BIRP services that span a diverse range of service types, from specialist inpatient units to community-based rehabilitation, provided over a relatively long period of time by a broad spectrum of health professionals
- The inherent complexity of measuring patient outcomes given the interplay of clinical, behavioural, vocational and quality of life factors in brain injury rehabilitation
- The importance of other government and non-government providers in maximising the rehabilitation outcomes and achieving community reintegration and social participation.

6.1.1 A snapshot of the BIRP population

In the 2012 BIRD Annual Report of BIRP activity, the total number of BIRP clients was 3,322 (13/14 units). This is determined by adding the numbers of the following two groups:

- Total distinct BIRP clients admitted or discharged in the relevant reporting year (1,563) plus
- The total number of distinct BIRP clients who were neither admitted nor discharged in the reporting year (1,759). These clients will have a range of injury dates, ages, be involved in different settings of care and have varying levels of program intensity (for the purpose of the BIRD Report termed “continuing or registered clients”).

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2012 BIRP Client profile:

- The male:female ratio is consistently around 3:1 (in 2012 males accounted for 72% of individual client intakes)
- There were 6.3% indigenous client admissions with 45 males and 25 females
- 5-14 year olds (21%) and 15-24 year olds (23%) accounted for a large proportion of all client intakes, a similar proportion to previous years
- In 2012 new admissions represented approximately three quarters (78%) of all client intakes, a similar proportion to previous years
- Approximately two-thirds (65.7% in 2012) of client intakes occurred in the same year as the injury, similar to the proportion in previous years
- 81% of client intakes in 2012 had sustained a TBI
- The most common cause of TBI was motor vehicle related (34%) and together with falls and assaults accounted for approximately two-thirds of all intakes
- Metropolitan trauma hospitals accounted for a large majority (80%) of referrals to adult BIRP inpatient units and more than 90% of referrals to paediatric BIRPs
- Transitional living programs receive the majority of referrals from the trauma hospitals (38%) and 16.4% from other sources (predominantly external medical practitioners)
- The treating hospitals provided 31% of referrals to BIRP community teams with a large proportion (46%) coming from 'other' services, predominantly family/self-referrals and practitioners/specialists.
- Financial status ('compensable', 'non-compensable' and 'unknown') is not directly related to claim type in the BIRP data collection system. Over the last 3 years, the proportion of 'Unknown' financial status has been consistent at around 20% of the intake. This includes patients who are waiting to be approved for the scheme or waiting for police reports to be provided to complete the scheme application forms
- With available compensation status information, the analysis shows that the majority (more than 80%) of compensable injuries were MVA-related
- In addition, data shows that the majority of patients with severe TBI related to MVAs were compensable (around 60%), which is in contrast to the Non-MVA related severe injuries where only 15% of patients were classed as compensable. This trend has been consistent over three years.

6.1.2 A snapshot of BIRP activity by setting of care

Data is collected from BIRP services and reported annually. For the purposes of the BIRD Annual Report of BIRP activity, the settings of care have been described as: 'Adult Inpatient', 'Transitional Living (TLU/P)', 'Adult Community', "Paediatric Inpatient' and 'Paediatric Community'. Therefore, some clients are counted more than once, as clients typically move through different settings of care during their rehabilitation episode (length of service). "Adult Inpatient" is dedicated inpatient beds while "Paediatric Inpatient" is an in-reach service to acute care beds or in-reach sub-acute rehabilitation.

- In 2012, 13 BIRP units admitted a total of 1,168 clients to 1,438 episodes of care
- Nearly 90% of new clients **admitted** to the adult inpatient setting were within 3 months of injury and more than 60% of new clients admitted to the adult community setting were within 6 months of injury
- Nearly 90% of children admitted to the paediatric inpatient setting were seen within one month of injury and more than 60% of children were admitted to the paediatric community setting within 3 months of injury
- The episode of care length for the adult inpatient and TLU admissions is typically less than 3 months and the episode of care for the paediatric inpatient admission is shorter, typically less than 1 month
- The episode of care length for community clients is variable
- Available data shows that private residence is the predominant type of **discharge** accommodation and differences exist between pre and post accommodation types.
- Combined Functional Independence Measure (FIM) data from the Adult Inpatient units shows that clients improve in the motor and cognitive domains during their rehabilitation between admission and discharge. Further analysis shows that:
  - People with the longest length of stay generally arrive with the lowest total FIM scores and some of these people will achieve a substantial change during their rehabilitation stay
  - A large proportion of people make very significant motor improvements and often approach or achieve the maximum FIM motor score of 91 at discharge, however, only a small number of patients achieve maximum cognitive scores at discharge, reflecting the greater impact that TBI often has on cognitive function.

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6.2 Lifetime Care and Support Scheme Participants

The Lifetime Care and Support Scheme (LTCS) began in 2006 for children under 16 and in 2007 extended to include adults. People eligible to participate include those with a spinal cord injury, moderate to severe TBI, severe burns or blindness and multiple amputations. The Scheme provides funding for treatment, rehabilitation and care services to people severely injured in motor accidents in NSW regardless of who was at fault in the accident.

The LTCS Authority manages the Scheme with NSW Government Safety, Return to Work and Support governance. People of all ages with motor vehicle related trauma may be eligible for the Scheme and those with brain injury can be accepted and have a 2 year interim period before a final assessment of severity determines lifetime participation in the scheme.

As of 30 June 2013, LTCS Authority had 796 participants in the Scheme of whom 438 were accepted lifetime participants.

- Children are most commonly injured as pedestrians and over one third of adults in the Scheme were the driver when the accident occurred
- The age group with the strongest representation is the 15-19 years (17%) followed by the 20-24 years age group with over 14%
- The majority of the scheme participants had TBI:
  - 93% (78) who were under 16 at the time of the injury had TBI
  - 73.5% (523) who were adults at the time of injury had TBI
- Excluding interstate and overseas participants, 372 participants lived in Sydney, 102 in Newcastle with the remaining 273 living in other NSW regions.

Although the vast majority of LTCS participants with TBI access BIRP services, they represent a smaller proportion of the total BIRP caseload which consists of people with TBI from other causes and a small number of people with complexity following acquired brain injury.

6.3 HEET Report

The ACI Health Economics and Evaluation Team (HEET) prepared a report in February 2014 and updated in August 2014 that is attached.

Refer to Appendix G for:

- Analysis of current admitted inpatient sub-acute activity service utilisation and costs for the BIRP patient cohort
- Projections for future demand for services.

The paper draws on data from the Ministry of Health's Activity Based Funding (ABF) taskforce analysis of sub-acute activity in order to calculate and apply the National Weighted Activity Units (NWAUs) for funding purposes. In considering the HEET report it is important to note:

- Analysis of current admitted inpatient sub-acute service utilisation uses SNAP classifications and funding under the Activity Based Funding system. The classifications do not specify the type of brain dysfunction so acquired brain injury and traumatic brain injury cannot be separately analysed
- Paediatric patients are excluded because sub-acute NWAUs have not yet been applied to paediatric activity

The key findings of the current service utilisation are as follows:

- In NSW in 2012/13, there were 698 admitted sub-acute episodes of care with a SNAP classification for brain injury and this activity used 20,929 sub-acute bed days, representing an average length of stay (ALOS) of 30 days and totalling $20.79m in sub-acute ABF funding
- Activity in 2012/13 represented an increase of 5% in episodes and bed days on the 2011/12 levels with ALOS stable over the two years and the level of funding for activity increasing by 1%

The HEET report also discusses projecting demand for BIRP services. It describes the findings using a sub-acute inpatient modelling tool endorsed by the Ministry of Health (SiAM) which projects that:-

- Funding for episodes (activity) is projected to grow at 2% per annum (2011 to 2022)
- The projected bed days needed to meet that demand is projected to grow at 3% per annum over that time

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It also reports that another method of determining future demand for services is by analysing the incidence and prevalence rates. However, there is considerable uncertainty about the incidence and prevalence of brain injury in Australia. As the projected episodes in 2022 (600) using SiAM is almost equivalent to the current (2012/13) SNAP activity recorded for brain injury (698), this discrepancy, combined with the lack of an agreed incidence/prevalence rate, highlights the need for an additional piece of work on projection methodology. The HEET will facilitate identifying a preferred approach to a projection methodology for BIRP services which will:-

- confirm the patient cohort to be treated by BIRP services in NSW
- identify the datasets that will provide the most comprehensive picture possible to reflect current BIRP service activity
- identify the most appropriate projection methodology to project future service demand to inform service requirements.

This piece of work will be undertaken to inform the Solution Design phase for the BIRP project.

6.4 Australian Rehabilitation Outcomes Centre (AROC) Inpatient data

The Australasian Rehabilitation Outcomes Centre (AROC) is a joint initiative of the Australian rehabilitation sector (providers, funders, regulators and consumers) that commenced operation in 2002. It aims to develop a national benchmarking system to improve clinical rehabilitation outcomes in both the public and private sectors.

There is currently no specialised brain injury report.

At a 2013 meeting an initial data comparison was presented. AROC identified 16 services that provided brain injury rehabilitation in Australia and New Zealand including the three NSW specialist centres (BIRP) at Ryde, Westmead and Liverpool. AROC demographic data confirms that these specialised services work with a population different from the more general rehabilitation group and the data differences are provided in Table 6.

A brief overview of some AROC data examples are provided in Appendix M.

While reassuring that the specialised services are providing rehabilitation to the group that was intended in the establishment of the BIRP, the absence of a benchmark cohort hampers further comparison of the program or its effects. BIRD is currently involved in benchmarking common data elements for these inpatient adult services with a private specialist rehabilitation service in Victoria and the TBI Model Systems program in the United States.

TABLE 6 AROC Demographic data differences

The AROC Group covers a Different Age group	95% of BIRP clients are 64 or younger; 25% of the AROC group are 64 or younger; The average age of BIRP clients is 15 years younger than the AROC group
The AROC Group has different sex distribution	About 80% of BIRP clients are male; 40% of AROC Group is male
The AROC Group is not Traumatic Brain Injury	More than 90% of BIRP clients suffer trauma; Less than 50% of AROC group with comparable impairments suffer trauma
The AROC Group do not work prior to episode	75% (n = 350) of all community-dwelling clients attending the BIRP between April 2011 and July 2012 (N = 468) were in paid employment prior to injury and admission to BIRP services 24% of AROC Group were in the labour force prior to admission
The AROC Group are more dependent prior to episode	Only a small percent of BIRP clients receive support prior to admission (6% at RRCS); 38% of AROC Group are dependent on support prior to admission

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7. A Changing Context

The Brain Injury Rehabilitation Program now operates in a different environment from that at inception. The key changes include:

- The NSW Health governance reforms of recent years.
- The introduction of the Lifetime Care and Support Scheme
- The introduction of Activity Based Funding (ABF)
- The development and implementation of the ACI Rehabilitation Model of Care for NSW
- The trial site in NSW of the National Disability Insurance Scheme and recent changes to the structure of disability services in NSW

Rather than provide a comprehensive account of these major reforms, this section sketches out the key elements and considers their implications for the development of a revised Model of Care.

7.1 NSW Health governance reforms

7.1.1 The state-wide program

The BIRP was established at the outset as a number of independent services rather than a state-wide specialist service with a centralised program. Formal coordination structures for funding, governance and service quality were established that initially included the NSW Health Joint Management Committee and later, a NSW Health Selected Speciality Program with governance from the Primary Health and Community Partnerships Branch and assignment of a project officer to collaborate with NSW BIRP Directors and Managers to discuss and resolve issues of local and state-wide concern.

A change in state government triggered organisational changes in NSW Health with the clinical governance transitioning to ACI for the BIRP network.

7.1.2 The funding arrangements

Specialised brain injury rehabilitation services in NSW were established with quarantined funding which was subsequently allocated as a recurrent budget to each LHD. NSW Health Finance branch has responsibility for the policy and annual review of the Schedule of Fees. The part funding fee for service model was introduced for sustainability of designated BIRP services. At that time the paediatric brain injury rehabilitation services were shown as a single entity and split between the 2 Sydney metropolitan hospitals, with four adult inpatient allocations being provided to Liverpool, Westmead, Royal Rehab at Ryde and Hunter.

The resource allocation formula (Milne, P. 2000)[30] used is based on the weighted population documented in the BIRP plan for each unit so percentage shares of the budgets could be provided. There was an allocation for all 16 of the then Area Health Services (now LHDs). In this Report Milne states that:

"The advantage of an activity model is that the data used are actual records of what has been done rather than a theorised version of what ought to be done. The disadvantage is that it completely ignores equity and may create a situation where people in some areas have access to services which others do not."

This means that under the ABF model, the establishment of a common set of data measures for activity and outcomes is crucial for the specialised rehabilitation program to receive an appropriate allocation of resources to manage the low volume and high cost of the target population if the resource allocation model changes from a population based weighted formulae to an activity model.

In addition, if ABF is directly implemented at a service level then other risks need to be explored to prevent disadvantage for the service and importantly, all of the BIRP service end users.

There has been no review of the resource allocation formulae for BIRP services since 2000 following the LHD restructure and the introduction of Activity Based Funding (ABF) so the impact on resource allocation is unknown.

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7.1.3 The governance of BIRP services

Organisational change in NSW Health has resulted in changed governance arrangements for the decentralised model of BIRP services over time. The program witnessed the establishment of the first wave of Area Health Services under the *Area Health Services Act 1996*, which gave Areas the responsibility for the arrangement and delivery of health services to the populations within their designated catchments and reduced the direct governance responsibilities of NSW Health for BIRP service delivery.

Following a number of Area Health Service restructures, including the abolition of the Area Health Boards, the most significant change has been the governance reforms in 2012 under which:

- Local Health Districts (LHDs), with smaller catchments and under the governance of local boards, have increased autonomy and accountability for health service delivery in their area. LHDs report directly to the Minister of Health
- The Sydney Children's Hospitals Network is a newly formed LHD bringing together the two paediatric hospitals (i.e., Randwick and Westmead) to have one major paediatric entity in Sydney
- The Department of Health became a smaller Ministry of Health providing traditional Westminster functions and acting as the 'system manager' and devolving some governance responsibilities to the four pillars and ACI for the BIRP clinical network.

Over more than two decades of operation there have been some structural changes in local arrangements of BIRP services. These have included a relocation away from designated and purpose built facilities, loss of some services initially established during the implementation phase and the development of new or expanded services such as Hunter now having a metropolitan paediatric BIRP service, paediatric case managers for some rural clients and more recently, the North Coast BIRS being split into two separate services in December 2012 to match LHD boundaries.

Critically, as part of the governance reforms, the LHDs have greater autonomy in accountability for the services they provide. As the Ministry shifts to purchasing health outcomes (as opposed to services) via performance agreements with the LHDs, all specialist health programs, such as the BIRP need to be included in key performance indicators; and the assessment of patient activity and outcomes needs to be reflective of the type of specialist activity being provided, so that BIRP services are able to accurately demonstrate the health benefits for the funding investment.

Importantly, BIRP services are provided to clients and families who live outside of the LHDs holding the funds for the operation of BIRP services. To ensure equity of access for the people of NSW with TBI, systems and processes to manage cross border service delivery need to be explored so funding practices can be implemented in a fair and transparent manner.

7.2 Lifetime Care and Support Scheme (LTCS)

In NSW there are two insurance schemes for people injured in motor vehicle related accidents. The NSW Motor Accidents Authority is a regulatory body for insurers of compulsory third party (CTP) motor vehicle claims. CTP is a fault based injury compensation system. Since 2006/7 all people severely injured in motor vehicle accidents that meet Scheme criteria and regardless of fault will be managed by the Lifetime Care and Support Scheme (LTCS).

The LTCS is funded by a levy on green slips to pay for treatment, rehabilitation and care for people who have been severely injured in a motor accident in NSW. This no fault scheme provides interim participation following a motor vehicle accident for up to 2 years before needing to be assessed for lifetime participation. As at 30 June 2013, 142 of 965 people have exited the Scheme and 27 have died.

Fee for service payments are provided for BIRP services as outlined in the NSW Health policy directive (PD2014_019). The range of health interventions includes but is not limited to, bed day rates for dedicated inpatient and transitional services, treatment and medication following discharge, individual and group based therapy, community rehabilitation involving a range of clinical and support staff, case management, client and clinician travel as well as equipment for daily living, home and vehicle modification. Care services includes but is not limited to personal care, respite services, childcare, domestic assistance and educational or vocational support.

The major implications of the scheme for BIRPs are that:

- During the critical 2 year post injury recovery period people with severe TBI caused by motor vehicle accidents on NSW roads have easier and timely access to treatment, rehabilitation, care and support services
- There is an increased workload burden for BIRP medical staff, clinicians and case managers arising from the LTCS legislation requirements for assessment, treatment and rehabilitation planning; liaison; documentation and reporting that cannot be completed by non-clinical staff.

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7.3 Activity Based Funding

In 2008, the Council of Australian Governments (COAG) agreed to a national partnership on hospital and health workforce reform. At the heart of the reform package was the introduction of Activity Based Funding (ABF) which represents a shift from *input* funding to *output* funding; that is, hospitals get paid for the number and mix of patients they treat.

The basic elements of ABF are:

- Classification of patients into relevant clinical groups with homogenous costs
- Documenting the number of episodes of care for each patient
- Costing a representative number of patient episodes
- Determining a price for the average patient, which is set by the Independent Hospital Pricing Authority (IHPA) based on data submitted by jurisdictions across Australia.

The IHPA has identified four care streams for classification as resource consumption varies significantly across these streams: (i) emergency department services, (ii) acute admitted services, (iii) sub-acute and non-acute care admitted services, (iv) non-admitted services and outpatient services. The BIRP provides a continuum of care that has elements of sub-acute and non-acute care admitted services, non-admitted services and outpatient services. ABF for the non-admitted and out-patient streams is being phased in from 1 July 2013.

To enable comparison of costs across and within care streams, the National Weighted Activity Unit (NWAU) was established to standardise prices and to allow LHDs to track activity across all care types.

Over time, the intention is to shift from seeing ABF as primarily a *funding* mechanism to a *management tool* (ABM).

The key implications of ABF and ABM for the BIRP program are:

- ABF is premised on the price of a clinical classification being an accurate reflection of the actual cost. In circumstances where specialist services cannot be accurately classified due to the limitations in coding then the price allocated to the activity will not be accurate
- Over time, the shift to ABM will involve a transition from efficiency to value for money which, necessarily, involves measuring effectiveness or patient outcomes.

Critically, Models of Care and best practice should drive ABM and not the reverse: that is, service delivery should not be dictated by the ABF funding envelope; rather, the funding model should reflect best practice, as articulated in an evidence-based Model of Care. This fundamental principle underscores the importance of including ABF development into the specialised Model of Care for BIRP services.

7.4 National Disability Insurance Scheme (NDIS)

The National Disability Insurance Scheme (NDIS) is a new way of providing support for people with permanent and significant disability, their families and carers across Australia. The NDIS commenced on 1 July 2013 with four launch sites, including the Hunter in NSW.

As it is in its infancy, it is premature to be definitive about the implications of the NDIS for the health sector and, specifically, the BIRP. Currently BIRP staff in the NSW trial area are providing advocacy and support to assist BIRP clients and their families/legal guardians with the NDIS application and assessment processes.

However, what is clear from the underpinning principles, agreed by government, is that the NDIS will not fund medical treatment or rehabilitation which will continue to be the responsibility of state health services, or provide services and support for people who qualify for injury insurance.

In NSW Aging Disability and Home Care (ADHC) provided some of these programs following health events as a continuum from health to community. People recovering from TBI could qualify although their ongoing level of disability may have still been unknown. This may be a critical issue for people with TBI, particularly those who have mild and moderate injuries who have previously been able to access ADHC programs during recovery and resettlement as they may not meet the “permanent and significant disability guidelines” of NDIS.

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The implications for people in NSW injured in motor vehicle related trauma are as yet also unknown. There appear to be differences between acceptance criteria and support available from NDIS and what was being accessed under ADHC in NSW. This is of significance as ADHC provided services and supports for the gaps between living with permanent disability and the treatment, rehabilitation and care costs provided by the LTCS.

This means that children, young people and adults of working age with severe brain injury acquired in MVAs accessing treatment rehabilitation and care under LTCS will be excluded from disability services to meet any additional needs (e.g., personal and family support services, accommodation, non-vocational leisure and recreation pursuits, respite care) and needs not related to the trauma (e.g., pre-existing illness, intellectual disability etc.). This may impact on hospital length of stay and could result in readmissions to manage changing community living circumstances.

While these concerns relate to disability in general rather than to the BIRP specifically there may be a loss of specific programs to transition from health to the community in a timely manner when accessing needed support services while recovering from a health event. This would exacerbate issues for transition home with the potential for extended inpatient stays or readmissions to manage risk and complications arising from inappropriate or inadequate service supports.

NSW Health is working collaboratively with NDIS to clarify the interface between these two service systems and to provide an interagency approach to manage the disability service restructure in NSW.

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8. Findings

A series of consultations with a range of stakeholders was undertaken during the diagnostic project, from which key strengths and issues with the delivery of BIRP services have been identified:

8.1 Strengths

A number of strengths were commonly highlighted in survey responses and site visits, including:

- The value to clients and families of having a specialist rehabilitation service and being able to return when needed
- The client and family centred approach provided by the BIRP
- The goal-oriented approach underpinning service delivery, that includes specialised case management as a core component of the rehabilitation program
- The active commitment to an interdisciplinary Model of Care involving skilled and experienced health professionals
- The spectrum of services in BIRP that spans inpatient through to longer-term community-based rehabilitation across metropolitan and regional teams
- Having specialist adult and paediatric streams within the program
- The involvement of families and carers in service planning and delivery
- The role of the Brain Injury Rehabilitation Directorate in engagement with BIRP clinicians for service and professional development.

8.2 Issues

The following list is a summary of the key issues for the operation of the NSW Brain Injury Rehabilitation Program that has been described in section 6.

1. Documentation of the Model of Care lacks cohesion and is not easily accessible

Although services commonly refer to 'the BIRP Model of Care', there was no easily available state-wide documentation of the actual model that brings together all of the different aspects of BIRP development. Information was spread across a number of different types of documents and reports. The absence of an easily accessible documented Model of Care can lead to variation across health service boundaries and gaps in service if the common understanding of the model varies.

Significant documents identified included the 1987 Cuff Report, supported by the 2004 Greater Metropolitan Clinical Taskforce report "Access to the New South Wales Brain Injury Rehabilitation Program". The 1992 'Standards for the NSW BIRP' used during establishment was also a key document but was not widely available now that these accreditation standards have been incorporated into district wide processes. Other documents are used to highlight certain points in this document and are listed in the references section.

In the survey almost half of the services (7) reported having a formal care pathway, clinical protocol or Model of Care, yet many of these were missing elements of the framework used in the current understanding of a Model of Care. The operation of the BIRP is well known and different aspects of the MOC have been incorporated into articles and presentations. There is cohesive description of the state-wide service in current Model of Care terminology.

The NSW Rehabilitation Model of Care is documented and is currently being implemented in LHDs. However, it does not fully align with BIRP service settings of care for BIRP transitional rehabilitation services. Unlike for Ambulatory Care (Day Hospital) the definition of the Ambulatory (Home Based) setting of care does not include the option for a comprehensive rehabilitation program conducted by a multi-disciplinary team (MDT) with the person in their home and community environments.

The BIRP does not have all of the settings of care in the network of BIRP services (e.g., no intensive ambulatory (day hospital) service).

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2. Funding complexity and inequities across NSW impact on meeting client needs

Significant variations in the resourcing of BIRPs across the state have led to concerns about the equity of access to services and the current distribution of services, particularly in rural locations and paediatric services.

BIRP services are relatively unusual in the health sector in that a proportion of clients (approximately 25% in 2012) are funded for their care by the Lifetime Care and Support Scheme (LTCS, see section 6.2). The remaining patients are funded via the recurrent budget and, more recently, via Activity Based Funding (ABF, see section 6.3). There are concerns about the implications of ABF and whether it will be able to capture all of the specialised brain injury rehabilitation intervention, particularly for client related activities and working with families.

The clinical outcome data needed to demonstrate patient outcomes are being met have not been clarified for reporting under ABF. BIRPs currently collect data relevant to the TBI population that could be useful for determining how to maintain funding levels into the future. Some data will be accessible. Will there be a link between ABF and outcomes collected by BIRPs or will there be other clinical indicators?

While private health insurance is considered in ABF, the revenue from LTCS is not included in ABF. Income derived from BIRP service revenue has been used to broker client services, respond to changes in demand, increase staffing and develop new ways of working with this challenging client group.

There is, however, considerable variation across LHDs, in their treatment of revenue collected by compensable clients. Although income increased in 2006/07 with the introduction of LTCS and more people being admitted to hospital under this Scheme, the income is not systematically returning to support BIRPs to meet growing demand and service expectations of the funders. For example:

- Some BIRP units are able to retain at least some of this revenue for staffing and service development
- In other LHDs the revenue is retained as part of the LHDs general operating budget
- Some BIRP units are required to meet a revenue target in order to achieve a pre-determined budget.

These differences in financial management policies align with the NSW Health governance reforms under which the LHDs operate more autonomously. However, it does mean that patients with TBI can have differential access to specialised rehabilitation services across the state and some stakeholders noted that the lack of flexibility with the current funding model can lead to extended staff vacancies and reduced productivity causing a loss of revenue.

3. Variation in staffing for similar BIRP settings of care impacts on service availability in some areas of NSW

The staffing of BIRP teams for different settings of care varies as an outcome of historical development, organisational and funding changes, and the ability to recruit staff to key positions and services.

In addition, when difficulties with clinician recruitment occur these cannot easily be filled by available local public or private clinicians as they often do not have specific skills working with adult and paediatric clients with ABI/TBI.

In rural areas, community staff have dual roles of case management and therapy. Case management is the core role with the allied health role changing based on available applicants. For example, a case manager/occupational therapist leaves and is replaced by a case manager/physiotherapist. This can change the team composition of therapy skills available (e.g. 2 physiotherapists and no occupational therapist in the team).

In two rural areas the LHD/hospitals recruit case manager roles with no allied health component for the BIRP community setting of care and do not recruit for these dual roles. In this situation clients may not be able to access specialised therapy services within the LHD/hospital they are located in or within the community. Local public or private clinicians often do not include people with ABI/TBI as a priority or have specific skills working with adult and paediatric clients with ABI/TBI. The client does not receive the therapy they need at the right time.

There is a need for greater clarity about what constitutes the core staffing mix, level of experience and staff profile for each setting of care operating within the BIRP model of services. Transitional programs and non-admitted services reported not working to any specific staff/patient ratio although some felt that it would be useful to have a recommended workforce ratio or at least have some agreement on the type of staff (discipline or role-specific) required to provide evidence-based multi-disciplinary teams that span the spectrum of brain injury rehabilitation services.

The BIRD is currently developing a community workload tool to assist management of caseload complexity.

4. Lack of culturally appropriate services for Aboriginal clients

There is a lack of culturally appropriate services for Aboriginal clients who are proportionally under-represented across transitional and community programs, and when admitted to BIRP services have higher rates of program non-completion than other BIRP client populations. Contributing factors include a lack of culturally appropriate TBI information, rehabilitation

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programs and resources to support Aboriginal clients and their extended families in hospital and after returning to the home, school or work.

This means that the Aboriginal person, their family and community may not have gained sufficient understanding of brain injury and the consequences for the individual so may struggle to manage the impact of changes in everyday situations.

5. Variable processes and resources to support 15-19 year olds, including their transition to adult services

The cohort of 15-19 year olds are seen by some services to 'fall between' paediatric and adult services with neither service being ideally placed to meet their needs. The process for transition varies between services with some services reporting that there is no clear pathway and that the different model of support available in adult services is confronting for young people and their families.

As a result, young people may not receive the support and intervention needed to manage the transition to decision making and independence or transition from education to employment. This may result in poor social outcomes and even involvement of the criminal justice system.

6. Limited consumer input to service planning

A number of BIRP settings of care have mechanisms in place for consumers to contribute to local service planning and review, including the use of satisfaction and service evaluation forms for improving performance. However, there was a common perception that a more cohesive and systematic approach to consumer engagement was needed at the local and state levels.

7. Structured program of professional development

Although significant professional development opportunities were attributed to the BIRD, some services, especially rural services, reported difficulty in attending training and would welcome a structured program that provides opportunities to visit other services and access mentoring and professional development with experienced staff in the same discipline, position or program. In addition, building skills and translating research into clinical practice for BIRP clinicians is problematic as there are a lack of workplace educators or trainers to build on knowledge gained externally.

Some services reported providing training and information to their linked referral organisations on TBI and rehabilitation whereas others reported that they would like to do more of this but that they were limited due to capacity and a lack of approval to travel and financial support.

Training resources for working specifically with TBI clients and their families were often not available so first needed to be developed for use in supporting clinical practice and professional development. Resources were often only available internally to disciplines or units and not shared across the network, perpetuating variation in practice between services.

Building capacity in local public and private clinicians in working with people with ABI/TBI is problematic as there are limited affordable education and learning opportunities or online resources for clinicians using adult learning principles.

8. Limitations in using information technology in everyday practices

Using technology to improve access to therapy, medical reviews and maximise resource allocation can be problematic due to health security rules and working across LHD boundaries with different levels of access and programs in operation. There are also issues of confidentiality and training and support for both the clinician and service user to manage more complex activities online. Limited research and evidence based practice guidelines are available for therapeutic intervention using new IT equipment and resources.

The opportunities provided by expanding IT capabilities are not consistently available, affordable or sufficiently networked to provide workable options. Problems of social isolation, distance and a lack of friendships could be reduced if clients and carers were engaged in using and accessing IT initiatives for support and networking.

Some services do use IT for therapy and networking for meetings etc, with professional, clients and family using telephones, emails, videoconferencing and Webex. Skype is more readily available for private clinicians not working in health. Funded projects are useful for building knowledge and awareness but resources to implement new ways of working with IT resources into everyday practice are limited and may not be accessible by clinicians working across LHD boundaries.

Clinicians and consumers consider that there are opportunities to explore greater use of IT with clients such as linking with clients for consultations, social media and Facebook. Services reported that there should be greater opportunity to explore the potential benefits of technology equipment and apps for clients to readily access services.

9. Low 'profile' of BIRP in comparison to other high volume health groups.

Reports from stakeholders are that brain injury and the BIRP seem to have a lower 'profile' relative to other clinical groups that have clearer pathways and larger referral numbers. Services external to BIRP aren't familiar with brain injury rehabilitation and the services available.

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LHD management are often not aware of the important relationship between BIRP services and the injury management sector for sustaining revenue-raising services and staffing. Hospital and district wide decisions can negatively influence service delivery and team configurations. This can impact on timeliness of admissions, discharges, treatment and therapy programs with an associated loss of revenue income.

10. Transfer of care and distance are barriers to accessing services close to where the person lives

BIRP services operate for all of NSW and provide services for people living outside of the district within which the BIRP service is located.

Although there are set geographical boundaries for different service types, and strong links between inpatient and community teams in the same BIRP, rural services reported that the referral links and engagement in discharge planning were sometimes tenuous, loosely defined and person reliant.

Referral pathways and service networks for patients returning home to a rural location from a metropolitan BIRP can be unclear, often because of gaps in the availability of services to meet the needs of the client and their family/support network or hospital goals not readily transferring to the local setting. The variation in availability of specialised rural adult and paediatric BIRP services and limitations for shared discharge planning so that local knowledge is included in resettlement goals, can make discharge planning difficult. The variability in accessing the different types of BIRP services and the other treatment, health, rehabilitation and support services required by clients when they return home to rural NSW complicate discharge planning.

Extended length of stay in metropolitan units, transfers to the local hospital or BIRP readmissions can occur when the therapy and services needed are not available on transfer to the community.

11. Variation in application of the BIRP eligibility criteria

Although there are clear eligibility criteria for BIRP services and geographical regions for different programs and care settings, their implementation was found to be variable, both across units and within units depending on workload, resources and circumstances.

Variation in acceptance criteria exists for adult services in relation to lower and upper age limits. Adult services accept clients from 18 years of age or from 16 years if they have left school. A number of stakeholders felt that the upper age limit of 65 years was no longer appropriate in view of a healthier aging population. Variation in entry criteria provides flexibility in meeting the needs of local populations and/or for bridging gaps in access and equity that may be required to meet the needs of the individual and their family/network's needs for specialised brain injury rehabilitation services.

Variation exists in relation to the severity of TBI accepted into the service (e.g. mild, moderate, severe) and period of time since date of injury. People with more recent injuries are prioritised to provide a continuum of care while people with a severe or very severe TBI are prioritised over those with a mild TBI. The classification of severity of TBI is primarily clinical (documentation, history, imaging, presentation factors). Some services have local systems for managing the spectrum of TBI from mild to severe while some services assess and possibly accept people with complexity following a mild/moderate TBI, mostly as a community referral via a rehabilitation specialist clinic or in consultation between the referrer and service manager. Some services have a waiting list to manage new people referred who had their brain injury some years before. Other factors considered when clients are referred for BIRP intervention include time since injury, accommodation arrangements, level of complexity, client/family need, service/referrer resources, local circumstances and general rehabilitation service gaps. Variability in applying admission criteria and poor communication about the outcome of referrals may cause confusion when different decisions are made for similar referrals.

12. Limited in-reach to acute setting and delayed referrals to BIRP

Metropolitan paediatric BIRPs have a notification system to monitor admissions and identify children and young people in need of additional specialised brain injury intervention soon after injury. Paediatric teams provide in-reach specialised brain injury rehabilitation early to maximise recovery and prevent secondary complications.

However, adult patients with extensive trauma or unstable medical conditions may not be referred to an inpatient BIRP service until many weeks after their injury occurs. During this time allied health services are available in acute care beds and the adult BIRP team will have limited involvement in the care of the patient. This is the same for those patients referred, accepted and waiting for admission. The intensity and scope of in-reach specialist brain injury rehabilitation services for adults in these circumstances varies. BIRP adult teams usually provide referral assessments, consultancy and liaison services with the treating team for planning care and the provision of information prior to discharge or transfer.

The early identification of patients with severe TBI admitted to trauma units or general hospitals is important for early engagement of the specialist brain injury rehabilitation services to promote accurate assessment, intervention and monitoring of recovery and/or appropriate care planning and transfer or discharge.

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Timing from referral to BIRP inpatient admission fluctuates as it is dependent on a number of factors influencing the waiting lists such as level of admitted patient needs and service capacity. Early referral to BIRP adult inpatient units are important factors for better managing patient flow and bed capacity.

In circumstances where brain injury goes unrecognised or undiagnosed (mild/moderate injury and multi trauma) patients and families often receive no or limited information about what to expect and what to do after leaving hospital. This results in confusion or anxiety about symptoms that may be a part of the recovery process and can cause preventable use of health services.

13. Timely and equitable access to BIRP services

Issues were raised about changing populations and service pathways that may be impacting on timeliness and equity of access to adult inpatient BIRP services at key points in the recovery and rehabilitation continuum. Questions included:

- Is the current number of adult inpatient beds sufficient to manage patient numbers and flow?
- What are the contributing factors for some people with severe TBI not being referred or admitted to inpatient adult services as a continuum of recovery?
- Patients who meet BIRP criteria and are not admitted to BIRP services may be disadvantaged by missing out on specialist intervention and not achieve their maximum potential for recovery. Some people will be referred to the community teams much later in their recovery when difficulties arise that could have been prevented by early engagement with BIRP services.

Young people not retrieved to the NSW paediatric trauma hospitals have difficulties being transferred when medically stable to an acute care bed in the paediatric trauma hospital to enable them to access in-reach paediatric brain injury rehabilitation services during the early stages of recovery.

14. Lack of dedicated inpatient rehabilitation beds for paediatric BIRPs

Although the majority of children and young people have a very short acute care stay following ABI in comparison to adults, some will need an extended inpatient stay to access the intensive therapy and hospital services they need while continuing to recover, while families have time to understand the changes and adjust and while care arrangements can be put in place for a planned discharge.

Extended hospital stays in acute care beds in paediatric trauma hospitals are disruptive for the child and family, limits the opportunity to enable practice of therapy and support in everyday situations as overnight and weekend leave is not possible and there is an absence of peer support for both the child with ABI and their families that happens when people with similar experiences are co-located.

15. Variation in accessing transitional living units/ programs (TLP)

The hours of operation and level of staffing can be a barrier to an early return to where the person lives. Transitional rehabilitation programs provide contextually based community rehabilitation options close to where the person lives. The therapy focus is assessment and rehabilitation for community resettlement to improve independent living skills and social participation. Services vary from standalone facilities with 24 hour non-nursing staff and a dedicated multi-disciplinary team to a program operating on hospital grounds with day staff only, to a community house with additional support and therapy services on a needs basis. Most TLPs operate a 5 day program in a modified home or health building. Some have no overnight support, adding further barriers to discharge planning, particularly for rural clients living some distance from the town where the TLP is located.

Transitional rehabilitation services operate from 8 of the 12 adult BIRP adult units and provide a higher level of program intensity than that provided by community teams. Community therapy services are usually less intensive and distance is a factor for BIRP clinicians visiting individuals and families at home, in school and community places. Integrated outpatient therapy program options are not currently available and transitional rehabilitation programs provide an appropriate alternative to remaining longer in the acute inpatient metropolitan services to access needed services and supports.

In some rural BIRPs clinicians work in both transitional living and community settings of care. This often means that intensive programs in one or other of these settings will reduce availability for the other setting of care so reductions in bed occupancy and program intensity will result.

16. Inequitable access following hospital discharge to integrated outpatient BIRP rehabilitation

Adults, young people and children benefit from access to intensive outpatient rehabilitation services as an alternative to inpatient programs. This can involve an integrated whole day specialised brain Injury rehabilitation program with individual and group therapy.

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Contextually based rehabilitation (occurs in real life situations) is well recognised as being more effective for managing the range of impairments generally seen following TBI.

Some BIRPs are organised to allocate a specific therapy team for outpatient services while others are able to arrange more intensive programs when needed.

The lack of an intensive outpatient therapy program is a reason for extending the inpatient stay in acute care or sub-acute care beds.

17. Inequitable access following hospital discharge to multi-disciplinary community therapy

The BIRP model has community-based case management and multi-disciplinary teams.

BIRP community teams do not include the same time allocation for clinicians and range of disciplines available across metropolitan, rural, adult and paediatric services. Team configurations affect the services available following discharge and may be exacerbated by short to medium term staff vacancies.

The ability of BIRPs to access and resource specialist metropolitan services or appropriate local providers is limited and challenging. There are limited metropolitan multi-disciplinary clinic services operating in support of adult and paediatric rural teams.

Return home can be delayed and programs compromised as a result of a lack of specialist clinician services at the right time.

18. Access to mental health services

Some people with TBI will be existing clients of mental health services and others may require these services for the first time after a TBI. A small group of people may be misdiagnosed and inappropriately directed to mental health services because of poor social behaviours.

Individuals with TBI can usually access mental health services while in hospital and when acutely ill. However, there is a need to better manage mental health and wellbeing from day to day. There is a need for BIRP and mental health clinicians to work better together and share knowledge to meet client goals for health and wellbeing by maintaining stability and preventing escalation and/or hospitalisation.

19. Limitations in Transfer of Care to non-health community services

Referral and access to community-based disability support services is sometimes difficult when the cognitive, psychosocial and behaviour support needs of people with ABI/TBI are not well understood and the services provided are not matched to the needs of the individual. In addition people with TBI (and their families) often need to engage with housing services for accommodation when their pre-injury accommodation is no longer viable, obtain housing, complete home modifications and receive specialist equipment before engaging with disability services. This can result in extended inpatient or TLP stays as well as readmission following a preventable crisis in management. BIRP services are providing a sustained level of maintenance case management support for some clients to maintain rehabilitation gains and prevent breakdown of health and community living arrangements.

The impact of the introduction of the NDS trial sites with subsequent ADHC restructure and program funding changes in NSW is causing uncertainty, particularly where previously funded client programs are not being approved as they are not meeting the NDS funding criteria. BIRPs may have an increasing role in individual advocacy in these circumstances.

20. Lack of low cost Carer/family accommodation

The BIRP inpatient and transitional services may be some distance from a client's home. There is a lack of access to low cost housing for families to participate in rehabilitation over extended time frames This is particularly important for Aboriginal clients and for families to support rehabilitation goals following a return home. Families need access to education training and practical support to understand how to assist their family member transition back home and participate in school, work and the community.

21. Barriers accessing equipment and home modifications

Following TBI some patients will require complex and customised equipment and /or home modifications for personal care, mobility and independent living. Waiting times and delays in accessing these resources when planning discharge can delay a return home. Access to the equipment, delays in decision making around application approvals and a lack of clarity on who are appropriate applicants form potential barriers to procuring the specific resources clients require to minimise the impact of disability so they can return home and access the community.

There are no formal pathways for communicating the needs of clients in state-wide specialty programs or partnerships for reducing the risk of inconsistencies in how brain injury clients are managed across different LHDs.

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8.3 Additional issues for Paediatric BIRP services

Representatives of the paediatric BIRPs noted a number of issues with the paediatric services which stand in addition to the previously identified key issues:

- The variability in levels of funding and lack of specialist paediatric services in most non metropolitan areas of NSW
- Limited access to and shortages of some services close to where the family lives, especially for paediatric metropolitan outpatient therapy services and paediatric medical and therapy services for rural BIRPs. This means that some children and young people will remain in hospital longer and will need to return to metropolitan BIRPs for ongoing treatment and review rather than identifying and accessing services closer to home
- The absence of dedicated inpatient beds meaning that children with brain injury who need longer hospital based rehabilitation intervention continue to be inappropriately allocated acute care beds and are not co-located with other children and families with similar needs
- The lack of day rehabilitation services for intensive therapy programs
- The limited availability of paediatric therapy services in the majority of the state and the lack of sufficient paediatric coordinators to manage high demand, such as the Illawarra
- The difficulty in being able to transition children to community rehabilitation because of limited services or lengthy waiting lists in the community.

8.4 Delivery of BIRP services across LHD boundaries

Consultation was undertaken with LHDs accessing BIRP services when these were not situated in their own LHD. This was to clarify their interaction with the program and to identify any issues with the existing arrangements. The key themes emerging were that:

- The BIRP does not have the same profile as other clinical groupings which often have clearer, better defined referral pathways and referral processes and there is a concern that some patients may be missing out on brain injury rehabilitation
- Awareness of BIRP services, referral processes and eligibility criteria may erode over time and with key staff changes
- Some LHD representatives considered delays accessing the adult inpatient units and transitional rehabilitation services resulted in patients remaining in hospital longer or being transferred to local hospitals inappropriately and admitted to general rehabilitation wards or acute care beds with limited or no BIRP engagement
- Some LHD representatives questioned whether the number of beds and location of inpatient units was appropriate for current populations
- There is seen to be a lack of clarity about the ‘catchments’ of the adult and paediatric BIRP services and different care settings with the new LHD structures and access for all people in NSW
- Adult and paediatric BIRP non inpatient services are inadequately resourced to meet the complexity of issues in rural and remote NSW or the additional issues experienced by Aboriginal people and people from diverse cultural backgrounds.

8.5 Service user representatives

The consumers, consumer organisations and service user representatives were consulted and noted a number of strengths with the NSW BIRP.

- Individualised program of rehabilitation based on client need and interests
- The value to clients and families of having specialist rehabilitation services and being able to return when needed
- BIRP intervention is delivered by a skilled workforce
- The model encourages consumer involvement
- The model supports education and training activities for staff.

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The current Model of Care was generally regarded as best practice with a highly skilled approach and benefits from a state-wide network of services that supports the professional development of staff. However, a number of service gaps or weaknesses were also reported:

- Although the upper age limit is evidence based for recovery and age, some people over 65 years could still benefit from the specialised brain injury rehabilitation approach
- Inequity in relation to acceptance criteria (age, ABI) and service availability for all NSW residents
- One consumer organisation highlighted a gap in relation to addressing the sexuality and relationship needs of clients and their families during rehabilitation
- There is limited consumer engagement at local and state levels
- There is no fee paid for consumer engagement which is restrictive
- Concerns that issues identified in research and projects are not addressed and recommendations are not implemented (e.g., 'Acquired Brain Injury Rehabilitation Service Delivery Project: Developing a Model of Care for Rural and Remote NSW').

A key issue raised by consumer organisations/consumer representatives was that whilst BIRP was seen to encourage consumer involvement, there is a need for broader **engagement.**

While there are mechanisms for client input and feedback on services, consumer representatives, along with a number of BIRP clinicians saw an obvious need for a more structured and systematic approach to support engagement at all levels of the clinical network so consumers are active partners in policy and decision making structures.

ACI values patient and family experience when engaging with consumers in health service planning and delivery. Engagement is the foundation for consumers working together as equal partners for improved service delivery outcomes and in other matters that have a significant impact on individuals with brain injury, families, carers and communities. Partnerships are dynamic and change in response to context, purpose and as the relationship matures.

Working collaboratively with the ACI Patient Experience and Consumer Engagement team in the different clinical redesign stages of the Model of Care review is an important element for establishing and sustaining a meaningful consumer engagement strategy.

Further consumer consultation is required to better understand the patient and family experience and to engage in co-design for building a better brain injury rehabilitation service system for all people accessing hospital services as a result of a TBI.

8.6 Workshop with NSW Health LHD Nominees

A workshop was held in April 2014 with representatives across NSW Health, including BIRP service representatives, to discuss a list of BIRP principles and an issues paper setting out the key themes emerging from the literature review, BIRP service surveys, visits and stakeholder consultations (see appendix K for an elaborated version of the issues paper). In line with the aims of the diagnostic project, the purpose of the workshop was to review and prioritise the issues arising from the diagnostic project to inform the next stage of the development of a revised Model of Care – the solution phase – and this section summarises the conclusions of the workshop.

8.6.1 The workshop participants considered a list of BIRP service principles located on the ACI website

Only some of these principles were discussed and participant feedback is provided in Table 7. A more systematic review of the BIRP service principles than was possible at the workshop is required. This review needs to consider the current health frameworks and approaches as well as the existing BIRP principles from the website, in reports, standards, and other documents arising from the establishment of BIRP services as well as subsequent journal articles and reviews.

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TABLE 7 Stakeholder feedback for BIRP principles

BIRP Principles	Stakeholder Comments
Equity of access to rehabilitation	• Terminology - agree with access to rehabilitation but may not always be brain injury service • Concept for the lay person, a state-wide service is available to everyone but within BIRP is not correct - access varies depending on unit - does not explain different programs, eligibility criteria or TBI/ ABI etc.
Needs-driven rehabilitation Goals of rehabilitation are not dependent on initial injury severity, but rather the nature and degree of disablement. There are no time limits provided on the length of time support is provided and programs are provided in a flexible manner	• Is this appropriate? - depends on resources • Inconsistent with Activity Based Funding environment
Goal-based rehabilitation Goals of rehabilitation are multi-dimensional, representing the sum of client-expressed need and third-party identified needs	• Client centred and client directed are also appropriate terms in goal based rehabilitation
Continuum of care Coordinated transition is provided between the relevant components of the continuum of care from acute inpatient rehabilitation to long-term support	• Expand to include collaboration with external providers e.g. LTCSA
Family-centred approach Families are viewed as partners in the rehabilitation process and typically the greatest resource available to the person.	• Omit “the greatest resource available to the person”
General comments	• Limited staffing and other service resources can reduce the capacity of programs to respond to demand and reduce flow through services. This can cause waiting lists and even result in an inappropriate early discharge home • is biopsychosocial a better rehabilitation descriptor to include? • Are the principles consistent with the rehabilitation Model of Care? • Should the principles reflect the specialist workforce? • Is there sufficient access to specialised staff for brain injury rehabilitation Model of Care? • Does the link with prevention and community education need to be more transparent?

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8.6.2 The issues paper discussed at the workshop was structured around a service continuum (appendix K)

The BIRP service continuum includes acute admission, BIRP inpatient units, paediatric in-reach and sub-acute services, transitional living programs and community-based rehabilitation teams.

While the workshop broadly endorsed the setting of care elements for organising issues in the discussion paper, two figures are included in the report to reflect differences between the adult and paediatric BIRP service components.

However, the figures do not adequately reflect the multiple entry and exit points in and out of BIRP services.

Following small group and plenary discussion of the issues and using a simple ranking process, the following five issues were proposed as priorities for development in the solution design phase:

- Equity of access and services (including funding)
- Referral pathways
- Early identification of people with brain injury
- Consumer engagement
- Multiple/co-morbidity (including recommendations arising from ACI projects).

8.7 Change of scope and more diagnostic work

A threshold question that emerged during the consultations with BIRP services, and was underscored at the April workshop, was whether a new Model of Care was required for the traumatic brain injury rehabilitation program or for people with traumatic brain injury requiring rehabilitation, including those who may not access the **program**, or be eligible to do so. The consensus was that the Model of Care should be structured around **people** whose needs should determine the system design. Moreover, it was noted that a focus on the program and services could neglect that proportion of patients who would benefit from brain injury rehabilitation but have not been referred because:

- There is not one clearly defined traumatic event but a cumulative number of different events resulting in changed brain function
- The services are not available
- Referring services are unaware of the BIRP for people with severe TBI
- They fall outside the BIRP eligibility criteria e.g. age or severity of injury
- The early intervention pathway following TBI is unclear or fragmented (Singh et al)[31].

The data available was insufficient to fully inform an expanded MOC framework for people with TBI regardless of age and severity. A new project needs to be initiated to identify the as is situation and use clinical redesign methodology to develop this MOC framework.

8.7.1 A Model of Care for all people with TBI admitted to public hospitals

The recommendation of the steering committee for the diagnostic project was that, ultimately, the Model of Care should cover mild, moderate and severe traumatic brain injury for people of all ages so that the different clinical pathways of the various groups and service involved are more clearly defined.

However, a staged approach is proposed, starting with the target group of BIRP services around which the current diagnostic report is configured. This segment of the total population is demonstrated in Figure 6.

The broader Model of Care framework will require collaboration with other service sectors and ACI networks (e.g., Emergency Care Institute) to document the different models that operate for people with mild and moderate injuries and the ACI Rehabilitation network for the over 65 years group.

Moreover, broadening the discussion to people with traumatic brain injury beyond the current BIRP service system enables the development of a new Model of Care to take account of the need for services to better integrate with primary health and community service systems. Such an approach is consistent with the increasing emphasis on integrated care, within and beyond the health sector, and on the phased implementation of the NDIS.

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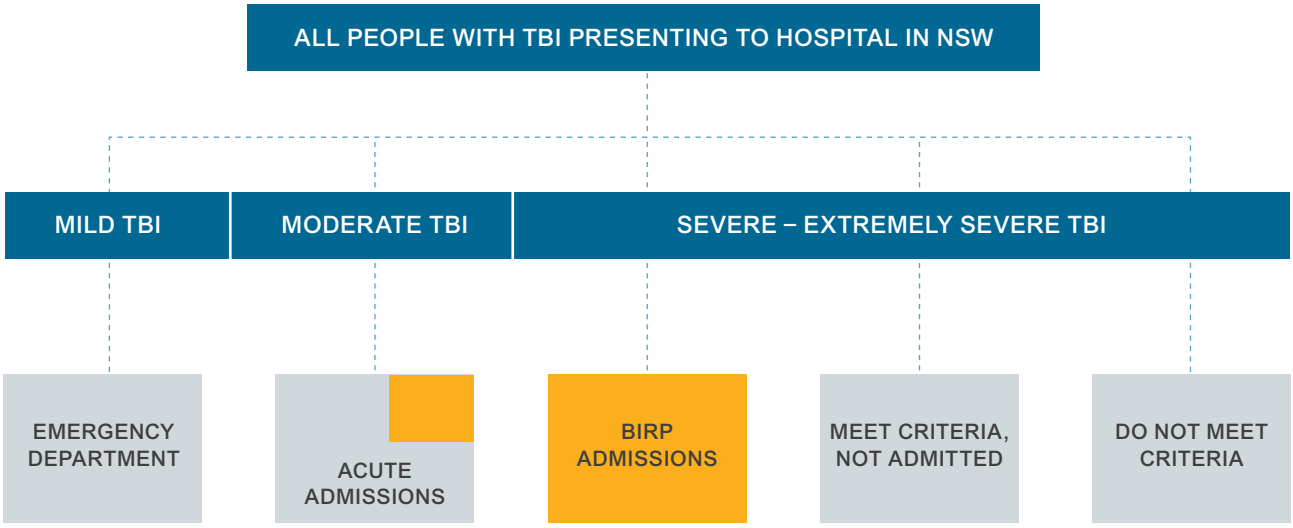
FIGURE 6 Change in Model of Care scope



*Shaded areas are the people with TBI included in the current BIRP Diagnostic Project

BIRP ADMISSIONS

8.7.2 The NSW Rehabilitation Framework and the TBI Model of Care

The definition of rehabilitation used in the development of the NSW Rehabilitation Model of Care excludes a large number of clients with TBI who participate in the specialised brain injury rehabilitation services. There is a need to work in collaboration with the rehabilitation clinical network to align the BIRP Model of Care and the new MOC for people with TBI admitted to hospital so that these models are complimentary and differences are valued and promoted within an appropriate framework.

The Model of Care for all people with TBI will be integrated by following the patient journey starting with hospital presentation, identifying the pathway for mild and moderate TBI, the transfer of people with severe TBI who meet criteria to the BIRP services or admission to other rehabilitation services and the extension of services into primary care and beyond health into other areas of government responsibility (housing, disability, school and tertiary education, employment).

In this context, the development, and implementation, of a Model of Care for people with TBI needs to be collaborative and have the active involvement of LHDs (who have authority over operational matters such that a proposed model cannot be mandated or prescribed state-wide). Other ACI networks (e.g., Rehabilitation Network) and institutes (e.g., Institute of Trauma and Injury Management and the Emergency Care Institute) will be important partners in this proposed framework for Model of Care for people with TBI.

The Rehabilitation Network are currently engaged in the implementation of the general rehabilitation Model of Care.

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9. Model of Care: Next Steps & Priorities

In developing a revised Model of Care, the BIRP has a sound foundation. Our consultations showed that NSW was seen as a leader in brain injury rehabilitation, as acknowledged by the consumers and stake holders consulted. The literature review suggests that the basic elements of the NSW system, as proposed in the Cuff Report, remain as relevant as ever in meeting the unique and complex needs of people with traumatic brain injury. The basic model encompassing a range of inpatient beds, outpatient services, transitional living units and community-based rehabilitation that are staffed by specific interdisciplinary teams provides the building blocks for a revised Model of Care.

This situation is partly a function of the history of the program. As outlined in section 4.2, a conscious decision when the program was established was to build a decentralised brain injury rehabilitation program. Indeed the early services were funded on the basis of submissions, rather than a systematic needs-based planning approach and as a result, the mix, resourcing and staffing of services across the state varied considerably. To some extent, this allowed BIRP services to be responsive to local needs and priorities and it avoided the problems of 'one size fits all' model. Nevertheless, some 21 years later the existing distribution and configuration of services largely reflects the historical legacy despite the significant changes in organisation changes and service developments since that time. The absence of a readily available and transparent Model of Care has been partly offset by the shared understanding of the BIRP model, NSW Health and more the work of the ACI Brain Injury Rehabilitation Directorate building a more cohesive, coordinated system which were evident and commonly acknowledged in consultations.

9.1 Next Steps

6 recommendations are provided:

1. Utilise the Diagnostic Report to move to the solution design phase of clinical redesign. Gaps and areas for improvement can be identified for stakeholder consultation to improve different aspects of the BIRP Model of Care
2. As soon as possible ACI to convene a BIRD working group involving Australian Rehabilitation Outcomes Centre, ACI Health Economics and Evaluation Team, NSW Health Activity Based Funding Taskforce and BIRP representatives, to explore the existing data to better understand the population, hospital flow and patient related outcomes for finalising the Model of Care and to include ABF development into the specialised Model of Care for BIRP services for solution design
3. Commence formal documentation of the BIRP Model of Care for children, young people and adults under 65 years with TBI admitted to BIRP services in consultation with key stakeholders to build on existing knowledge and understanding. The Model of Care will clarify referral and acceptance criteria, provide clear access and pathways information and provide for a more integrated, cohesive and coordinated service system
4. To engage the ACI Patient experience and consumer engagement (PEACE) team to implement a measurable consumer engagement policy, at both state and local levels, that delivers meaningful involvement of end users in BIRP service planning as well as BIRP service delivery
5. ACI commission a diagnostic project to better understand factors influencing decision making for clients who fit BIRP criteria and are not referred or admitted; those who do not fit criteria but are referred with some admitted
6. ACI to initiate a clinical redesign project to develop a framework for all people, regardless of age, who present to hospital following a traumatic brain injury (TBI) with any level of injury severity.

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Recommendation 1: Utilise the Diagnostic Report to move to the solution design phase of clinical redesign. Gaps and areas for improvement can be identified for stakeholder consultation to improve different aspects of the BIRP Model of Care

- Incorporate the use of traditional needs-based planning tools that take account of the population base and other demographic features of different parts of the state in combination with measures of community need and projected demand
- Review the current equity and access available given the distribution of adult and paediatric BIRP services across the state and recommend minimum service level standards across the continuum of specialist brain injury rehabilitation programs and different settings of care
- Take into account that specialist inpatient adult units and specialised in-reach paediatric services will necessarily have a state-wide responsibility and some transitional and community rehabilitation services will be available for supra regional clients
- Clarify the ideal staffing configuration of BIRP services to provide evidence-based interventions that span the spectrum of brain injury rehabilitation services and provide important information for providing the right service at the right time for people with TBI living in NSW
- Define the different program roles for specialised brain injury rehabilitation services and thus yield a standard or benchmark for LHD service planning.

The solution design phase will address particular issues emerging from the consultations that warrant attention before the Model of Care can be finalised. These include:

- Provide greater clarity about referral pathways to facilitate patients' smooth transition along a continuum of care
- Improve the early identification and notification process for referral to specialist adult inpatient brain injury rehabilitation units of patients with TBI when admitted to trauma units or general hospitals similar to what currently exists for paediatric admissions
- Identify any persons who meet the admission criteria for BIRP services and explore the reasons for non-admission and their treatment pathways
- A more consistent approach to in-reach and consultancy for adult acute hospital services would create stronger links between BIRPs and referring services to smooth the patient journey and help to start specialist rehabilitation earlier in the management of a patient's recovery and until admitted to BIRP Services.
- Referral pathways from metropolitan units to rural BIRPs closer to where patients reside
- A systematic approach for rural teams to access needed specialist medical and therapy services and support to manage the range of client needs when these services are not included in BIRP teams or being managed in generic health and community services
- The Model of Care incorporates referral and treatment pathways for people with TBI and either pre or post injury co-morbidities such as mental health or drug and alcohol issues
- Improve the management of income generated by the current part funding fee for service model and work collaboratively with NSW Health to ensure that the ABF calculations appropriately reflect the specialised activity and low volume, high cost client profiles
- Identify the staff and revenue resources required to provide specialist rehabilitation intervention programs that meet the needs of adults, children and young people.

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Recommendation 2: As soon as possible ACI to convene a BIRD working group involving ACI, BIRP representatives, AROC, HEET and the ABF Taskforce to develop an issues paper to better understand and further explore health data and ABF developments for informing the specialised TBI rehabilitation Model of Care.

- the clinical and coding issues for identifying admitted inpatient specialised brain injury rehabilitation sub-acute activity from the broader brain dysfunction classification
- the clinical and coding issues for reporting non admitted specialised brain injury rehabilitation sub-acute activity
- the funding and revenue implications for the BIRP services part funding model for participants of the Lifetime Care and Support scheme (LTCS) (see 7.2)
- Critically, Models of Care and best practice should drive ABM and not the reverse: that is, service delivery should not be dictated by the ABF funding envelope; rather, the funding model should reflect best practice, as articulated in an evidence-based Model of Care. This fundamental principle underscores the importance of including ABF development into the specialised Model of Care for BIRP services
- Benchmarking strategy with AROC data be explored, including developing reports at both comparable service and selected impairment and subgroup levels
- Develop a framework for cooperative information exchange with appropriate interstate, New Zealand and international TBI specialty rehabilitation services
- That reporting and similar benchmarking project be developed suitable for clients involved in Transitional and Community-based TBI rehabilitation services.

It is anticipated that development of an issues paper will involve key stakeholders from HEET, the ABF Taskforce, AROC and ACI and is required to better inform the solution design phase of the Model of Care review for sub-acute inpatient, admitted and non-admitted transitional rehabilitation services and non-admitted adult and paediatric BIRP services.

Recommendation 3: To commence formal documentation of the BIRP Model of Care for children, young people and adults under 65 years with TBI admitted to BIRP services in consultation with key stakeholders to build on existing knowledge and understanding. The Model of Care will clarify referral and acceptance criteria, provide clear access and pathways information and provide for a more integrated, cohesive and coordinated service system.

The fundamental issue that this diagnostic project has identified is that the basic architecture and the building blocks have not been sufficiently well articulated into a formal Model of Care. While BIRP service representatives clearly understand the continuum of care and ideal patient journeys, there was a notable lack of documentation that was easily accessible and clearly defined the key components. Much of this information is included in various reports, articles and online locations.

- The Model of Care will draw on the strengths of the existing BIRP service arrangements
- The model will incorporate the information arising from the expanded diagnostic regarding people who meet severity and age criteria who are not admitted to BIRP services
- The BIRP principles will be systematically reviewed and finalised by a consensus process, clearly documented and made widely available
- The continued engagement of LHDs is needed as they have authority over operational matters and cross border issues need to be considered for implementation
- Have the active involvement of the ACI Rehabilitation Network to ascertain how the BIRP specialised rehabilitation Model of Care aligns with the recently developed NSW Rehabilitation Model of Care currently being implemented, while acknowledging the special needs of children, young people and adults of working age (<65yrs) with severe TBI and the requirement for a different service response
- Include the issues and recommendations from the ACI network reports about the needs of people with TBI and challenging behaviour, living with ABI in rural and remote NSW and vocational Models of Care in the BIRP Model of Care.

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Recommendation 4: To engage the ACI Patient experience and consumer engagement (PEACE) team to implement a measurable consumer engagement policy, at both state and local levels, that delivers meaningful involvement of end users in service planning as well as service delivery.

While there are mechanisms for client input and feedback on services, consumer representatives, along with a number of BIRP clinicians saw an obvious need for a more structured and systematic approach to support engagement at all levels of the clinical network so consumers are active partners in policy and decision making structures.

ACI values patient and family experience when engaging with consumers in health service planning and delivery. Engagement is the foundation for consumers working together as equal partners for improved service delivery outcomes and in other matters that have a significant impact on individuals with brain injury, families, carers and communities. Partnerships are dynamic and change in response to context, purpose and as the relationship matures.

Working collaboratively with the ACI Patient Experience and Consumer Engagement team in the different clinical redesign stages of the Model of Care review is an important element for establishing and sustaining a meaningful consumer engagement strategy.

Further consumer consultation is required to better understand the patient and family experience and to engage in co-design for building a better brain injury rehabilitation service system for all people accessing hospital services as a result of a TBI.

Recommendation 5: ACI commission a diagnostic project to better understand factors influencing decision making for clients who fit BIRP criteria and are not referred or admitted; those who do not fit criteria but are referred with some admitted.

- This information is required to complete the MOC for people with severe TBI and to improve referral and access pathways to BIRP services
- The project to identify what and how rehabilitation services are being provided for the client and families to contribute to the MOC review.

Recommendation 6: ACI initiate a project to actively engage the ACI Rehabilitation and Brain Injury Rehabilitation networks in working collaboratively with consumers, clinicians and stakeholders to understand the current service delivery model for all people with TBI admitted to hospital. This overarching framework will incorporate the BIRP model of care.

- The BIRP Model of Care will sit within this framework for children, young people and adults of working age with severe TBI
- Developing an overarching framework for all people admitted to hospital following TBI will assist in understanding the interface between different health services in the patient journey
- Additional information from consumers and clinicians is required about the broader target populations and what are the current health pathways for the following client groups:
  - People of all ages with a TBI as evidenced by a period of post traumatic amnesia or neuroimaging and discharged from Emergency Departments
  - People of all ages admitted to a NSW hospital with mild and moderate TBI
  - People with severe TBI over 65 years
  - People with complex, mild or moderate TBI admitted to BIRP services
- There is a need to engage with LHDs, primary health, Enable NSW, other NSW government agencies and a range of ACI networks (e.g., Emergency Care Institute, Institute of Trauma Injury Management, Rehabilitation) to determine the “as is” situation for all people with TBI not meeting BIRP criteria

Initiating a project that broadens the scope of the current Diagnostic Report so that all people with TBI are included and documenting the different clinical pathways available will assist the delivery of the right service at the right time across hospital and primary health care settings. Such an approach is consistent with the increasing emphasis on integrated care.

The recommendations are not listed as priorities as all elements are needed to improve the patient journey from hospital to recovery for people following a TBI regardless of age and injury severity.

However, the first four recommendations arise from the current diagnostic and are key factors moving forward to solution design. Recommendation five addresses the issues of concern that were outside the scope of the current diagnostic project but are of direct significance to the solution design stage for the BIRP model of care.

Recommendation six is considered a new project that requires a range of stakeholders to commit time and resources to initiate this project across different health and community services for a greatly expanded group of people with TBI.

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10. Glossary

ABBREVIATIONS

ACI - NSW Agency for Clinical Innovation

BIRP - NSW Brain Injury Rehabilitation Program

BIRD - ACI Brain Injury Rehabilitation Directorate

LTCS - Lifetime Care and Support Authority/Scheme

NDIS - National Disability Insurance Scheme

SCHN - Sydney Children's Hospitals Network (Randwick and Westmead)

DEFINITIONS

Client /Patient refers to a child, young person (adolescent) or adult of working age (under 65 years) admitted to the network of specialised brain injury rehabilitation services, usually following a traumatic brain injury with complex and changing needs for recovery, community integration and social participation.

Families and its derivatives, includes direct and extended family members (not necessarily by marriage) and other significant social relationships in the life of the client. Families are important members of the rehabilitation team and can be direct recipients of BIRP services.

Local Health Districts (LHDs)

There are 15 Local Health Districts in NSW that are responsible for providing health services in a wide range of settings, from primary care posts in the remote outback to metropolitan tertiary health centres. Eight Local Health Districts cover the greater Sydney metropolitan regions, and seven cover rural and regional NSW. The LHD boundaries are provided with the location of BIRP services.

The Sydney Children's Hospitals Network (SCHN) is a newly formed LHD that brings together the two paediatric hospitals located in Randwick and Westmead into one major paediatric entity for Sydney.

Biopsychosocial Framework: An approach describing and explaining how biological, psychological and social factors combine and interact to influence physical health and mental wellbeing.

Rehabilitation: the action or process of rehabilitating or of being rehabilitated:

a) the physical restoration of a sick or disabled person by therapeutic measures and re-education to participation in the activities of a normal life within the limitations of the person's physical disability e.g., rehabilitation after coronary occlusion

b) the process of restoring an individual to a useful and constructive place in society especially through some form of vocational, correctional, or therapeutic retraining http://www.merriam-webster.com/medical/rehabilitation

- **Psychosocial Rehabilitation:** "Psychosocial rehabilitation involves rehabilitation interventions which help you to manage behaviours, perceptions and reactions to your injury or condition which may hold back the process of recovery or maintenance of your wellbeing. A rehabilitation program may focus solely on a package of psychosocial interventions. However, it is more likely that psychosocial activities will be offered in conjunction with medical and/or vocational rehabilitation services… Psychosocial interventions help address issues which can undermine and act as barriers to progressing rehabilitation."

  http://www.dva.gov.au/rehabilitation/rehabservices/Pages/Psychosocialrehabilitation.aspx

- **Social Rehabilitation:** "Social rehabilitation aims at getting people back into society"

  http://psychologydictionary.org/social-rehabilitation/

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11. References

1. Longworth, M. The Journey of Stroke Services in New South Wales 2002-2012. Paper Presented at the ACI Rehabilitation Network Forum October 2012. Retrieved from http://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0006/177351/Rehab_Forum_Mark_Longworth_-_Stroke_Services_overview.pdf.
2. Wood RL, McMillan TM, eds. (2001). *Neurobehavioural Disability and Social Handicap Following Traumatic Brain Injury.* East Sussex, England: Psychology Press.
3. Rosenthal, M. (1996). 1995 Sheldon Berrol, MD Senior Lectureship: The ethics and efficacy of Traumatic Brain Injury Rehabilitation: Myths, measurements and meaning. *Journal of Head Trauma Rehabilitation*, 11:88-95.
4. Cuff Consultants (1987). *A brain injury program for New South Wales: GIO's commitment under Transcover.* Sydney, Australia: Government Insurance Office.
5. Accident and Compensation Commission (2006). *Traumatic Brain Injury: Diagnosis, Acute Management and Rehabilitation.* New Zealand: New Zealand Guidelines Group, Accident and Compensation Commission.
6. Bayley, M.T., Teassell, R.W., Wolfe, D.L., et al (2014). Where to build the bridge between evidence and practice? Results of an international workshop to prioritize knowledge translation activities in traumatic brain injury care. *Journal of Head Trauma Rehabilitation*, 29: 268-276.
7. Maas, A., Stocchetti, N., Bullock, R. (2008). Moderate and severe traumatic brain injury in adults. *Lancet Neurology*, 7:728-741.
8. UK National Institute for Health and Clinical Excellence (2014). *Head Injury: Triage, assessment, early investigation and management of head injury in infants, children and adults. NICE Clinical Guideline 176.* Retrieved from www.guidance.nice.org.uk/cg176.
9. Khan, F., Baguley, I.J., Cameron, I. D. (2003) Rehabilitation after traumatic brain injury. *Medical Journal of Australia,* 178(6): 290-295.
10. Mitsch, V. (2011) *Acquired Brain Injury Rehabilitation Service Delivery Project: Developing a Model of Care for Rural and Remote NSW.* Sydney, Australia: Agency for Clinical Innovation.
11. Mitra, B., Cameron, P., and Butt, W. (2007). Population-based study of paediatric head injury. *Journal of Paediatrics and Child Health,* 43(3): 154–159.
12. Laxe, S., Zasler, N., Selb, M., Tate, R.L., Tormos, J. M., Bernabeu, M. (2013) Development of the International Classification of Functioning, Disability and Health core sets for traumatic brain injury: An International consensus process. *Brain Injury*, 27(4): 379 –387.
13. Savage, R.C., De Pompe, R., Tyler, J., Lash, M. (2005) Paediatric traumatic brain injury: A review of pertinent issues. *Paediatric Rehabilitation*, 8(2): 92-103.
14. Sander, A.M., Maestas, K.L., Clark, A.N., Havins, W.N. (2013) Predictors of Emotional Distress in Family Caregivers of Persons with Traumatic Brain Injury: A systematic review. Brain Impairment 14 (1) 113-129.
15. Degeneffe, C.D., Olney, M. F. (2010). "We are the forgotten victims": Perspectives of adult siblings of persons with traumatic brain injury. *Brain Injury*, 24(12):1416-1427.
16. Koenig, C. (2006). *There's Always Hope just alter the Dreams.* Sydney, Australia: NSW Department of Health.
17. Koenig, C. (2007). *Courage to Care*. (2007). Sydney, Australia: NSW Department of Health.
18. Mitsch, V., Curtin, M., Badge, H. (2014). The provision of brain injury rehabilitation services for people living in rural and remote New South Wales, Australia. *Brain Injury*, 28(12):1504-13. doi: 10.3109/02699052.2014.938120. Epub 2014 Aug 5.
19. Sabaz, M., Simpson, G.K., Walker, A.J., Rogers, J.M., Gillis, I., Strettles, B. (2013). Prevalence, comorbidities, and correlates of challenging behaviour among community- dwelling adults with a severe traumatic brain injury: A multicentre study. *Journal of Head Trauma and Rehabilitation*, 29(2):E19-30. doi: 10.1097/HTR.0b013e31828dc590.
20. McRae, P. (2013*). Investigation of Vocational Programs and Outcomes for people with traumatic brain injury in NSW.* Sydney, Australia: Agency for Clinical Innovation and Lifetime Care and Support Authority, NSW Government.
21. Government of Western Australia, Department of Health (2012). *A practical guide on how to develop a Model of Care, Agency for Clinical Innovation, Version 1.0,* Retrieved from http://www.agedcare.health.wa.gov.au/home/MOC.cfm, Accessed May 2013.
22. Australian Council of Health Standards (1992). *Standards for the NSW Brain Injury Rehabilitation Program.* Sydney , Australia: Australian Council of Health Standards..
23. Bosi, R. (2008) Planning Principles for a brain Injury rehabilitation Model of Care, Greater Metropolitan Clinical Taskforce. Unpublished. Sydney, Australia: NSW Department of Health.
24. NSW Health, Sydney (1999). The Brain Injury Rehabilitation Speciality Services Plan Discussion Paper. Sydney, Australia: NSW Department of Health,
25. Harradine, P.G., Winstanley, J.B., Tate, R.L., Cameron, I., Baguley, I.J., Harris, R.D. (2004). Severe traumatic brain injury in New South Wales: comparable outcomes for rural and urban residents, *Medical Journal of Australia,* 181(3): 130-134.
26. NSW Department of Health. (2004). The Report of the Greater Metropolitan Services Implementation Group. Sydney, Australia: NSW Department of Health.
27. Tandon, G. (2004). Access to BIRP services: A review of service provision across the Greater Metropolitan area. Greater Metropolitan Clinical Taskforce, Sydney Australia: NSW Department of Health.
28. Hopman, K. (2005). A Review of Transitional Living Programs in the NSW BIRP: Stage One Report. Sydney, Australia: Greater Metropolitan Clinical Taskforce NSW Health. Retrieved from http://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0011/159797/tlp_evaluation_report_stage1.pdf.
29. Hopman, K. (2006). A Review of Transitional Living Programs in the NSW BIRP: Stage Two Report. Sydney, Australia: Greater Metropolitan Clinical Taskforce NSW Health. Retrieved from http://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0012/159798/tlp_evaluation_finalreport.pdf.
30. Milne, P. et al (2000). BIRP Allocation of resources Centre for Health Service Development. Wollongong, Australia: University of Wollongong.
31. Singh, R., Venkateshwara, G., Kirkland, J., Batterley, J., Bruce, S. (2012). Clinical pathways in head injury: Improving the quality of care with early rehabilitation. *Disability & Rehabilitation*, 34(5): 439 – 442

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