

MODEL OF CARE

# NSW Brain Injury Rehabilitation Program: Case Management

Brain Injury Rehabilitation Directorate



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## Foreword

On behalf of the NSW Agency for Clinical Innovation (ACI) Brain Injury Rehabilitation Directorate (BIRD) Executive, we extend our sincere appreciation to the steering committee members both past and present who collaborated extensively over a number of years to document the model of case management in the NSW Brain Injury Rehabilitation Program (BIRP). Their work has resulted in the production of a valuable and extremely useful document that will improve our understanding and knowledge of the key role case management holds in the delivery of BIRP services. The collaborative approach of the steering committee has embraced clinician expertise and the most recent evidence-based research and is reflective of the clinical practice consensus among adult and paediatric BIRP case managers working in metropolitan and rural NSW.

Our appreciation also to the many others that contributed over time to this body of work, including people with brain injury admitted to BIRP services, their families and the clinicians working alongside case managers in BIRP teams.

The model of BIRP case management would not have been completed without an enthusiastic group of clinicians who identified the need to clarify and document roles. Our particular thanks are therefore extended to members of the very first working group who initiated the investigation at a small number of BIRP locations. They demonstrated the vision and understanding of the role of case management when working with people with brain injury and their families that has been the foundation for completing this model of clinical intervention.

This document enables the BIRD executive to move forward and develop education and training resources that support quality clinical practices in the everyday delivery of case management services in the network of BIRP services.



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## Executive summary

Case management in the NSW Brain Injury Rehabilitation Program (BIRP) is a collaborative process involving the coordination, rehabilitation, care and support of people with complex clinical needs admitted to BIRP services following a traumatic or acquired brain injury. It aims to facilitate clients' independence and improve their quality of life.

The BIRP provides the organisational framework for specialised brain injury rehabilitation case management.

A completed literature review identified best-practice models of community-based rehabilitation, with a particular aim of identifying case management approaches consistent with the scope and objectives of the BIRP. The method, results and conclusions are reported in Section 2. The primary conclusion drawn from the articles identified in this review was that the published studies have limited applicability to the context within which the specialised BIRPs operate in NSW.

All BIRP case managers provide a direct service model of clinical intervention within different team structures. The scope of BIRP case management is namely the extent to which it is combined or separated from community rehabilitation therapy services within the same BIRP.

This report describes the BIRP model of case management, including the aims, principles, definition and the 10 core elements of the BIRP model that have been benchmarked against the generic core standards of the Case Management Society of Australia. The client-centred goal planning approach used in BIRP services supports a practical framework for BIRP case managers to provide integrated care that exceeds the national standards.

The principles of BIRP case management are that it:

1. is driven by client needs
2. is directed by client goals
3. is community-based
4. is participation-focused
5. recognises family as members of the rehabilitation team and important contributors to the achievement of client goals.

These BIRP case management principles have strengthened client-directed goal-setting, which facilitates a collaborative approach to community participation. The five principles are consistent with the principles underpinning the state-wide delivery of specialised brain injury rehabilitation services (Section 3).

Case management within the BIRP developed from the ground up, in tandem with the establishment of the BIRP community rehabilitation teams in the mid-1990s. In the context of limited literature regarding case management outcomes, a project was initiated in 2007 to take a heuristic approach, developing a service model out of the existing experience and operations of case managers in BIRP community rehabilitation teams.

In 2010, a whole of network approach to finalising documentation of the BIRP model of case management was adopted and a steering committee convened by BIRD, a clinical network of the ACI. This report is the outcome of the work of this group.

Section 4 provides the clinical pathway for BIRP case management and describes processes in clinical intervention.

Key factors affecting the provision of BIRP case management services are described in Section 5. These factors can be barriers to achieving client goals for recovery, community integration and social participation.

## Executive summary

Client, staff and organisational factors as well as factors relating to children and young adults and the additional needs of Aboriginal people are described. This section also explores the impact of geography, particularly in rural and remote NSW, for accessing the right service at the right time by the right staff, as well as caseload factors that impact on BIRP case managers being able to meet growing and changing demands in service delivery.

BIRP case managers currently collect data to evaluate their intervention, for activity-based funding and to facilitate service management. Section 6 outlines the type and purpose of data collected. The model seeks to establish a consensus in developing standardised data collection, analysis and reporting by using occasions of service data, client data and standardised measures of outcome to measure individual outcomes and service performance.

Attracting and retaining the right staff is a workforce issue that impacts on team functioning and ultimately the quality and availability of BIRP case management services (Section 7). As part of the model a case manager profile was agreed by a process of consensus. This profile may assist in finding the right person for the job by making available a template for developing position descriptions and supporting recruitment processes. While it was beyond the scope of this steering committee to systematically map the training available to case managers and identify relevant and appropriate resources and gaps, this section does include preliminary information towards this goal. A separate defined project would be required for this purpose.

The references provided in Section 8 and Section 9 expand on the background and resources used in this project; the BIRP service context; and summaries arising from the literature review.

## Abbreviations and glossary

Abbreviation	Description
ABI	Acquired brain injury
ACI	NSW Agency for Clinical Innovation
ALO	Aboriginal Liaison Officer
AN-SNAP	Australian National Subacute and Non-Acute Patient
ASI	Addiction severity index
ASSBI	Australian Society for the Study of Brain Impairment
BIRD	ACI Brain Injury Rehabilitation Directorate
BIRP	NSW Brain Injury Rehabilitation Program
CANS	Care and Needs Scale (Adults)
CHN	Child Health Network
CIQ	Community integration questionnaire
CMgr/CM	Case manager/case management
CMSA	Case Management Society of Australia
CTP	Compulsory third party
DRS	Disability rating scale
DBIRP	Dubbo Brain Injury Rehabilitation Program
FIM	Functional Independence Measure
FTE	Full-time equivalent positions
HBIS	Hunter Brain Injury Service
HETI	Health Education and Training Institute
IBIS	Illawarra Brain Injury Service
ICF	International Classification of Functioning, Disability and Health
Kaleidoscope PBIRT	Kaleidoscope Paediatric BIR team (Newcastle)
LBIRU	Liverpool Brain Injury Rehabilitation Unit
LHD	Local Health District

Abbreviation	Description
LOS	Length of stay
LTCS/A	Life Time Care and Support Scheme/ Authority
MNCBIRS	Mid North Coast Brain Injury Rehabilitation Service
MPAI	Mayo-Portland Adaptability Index
MWBIRP	Mid West Brain Injury Rehabilitation Program
NBIRS	Northern Brain Injury Rehabilitation Service
NCBIRS	North Coast Brain Injury Rehabilitation Service
NCSE	Non-convulsive status epilepticus
NEBIRS	New England Brain Injury Rehabilitation Service
OOS	Occasions of Service
PCANS-2	Paediatric Care and Needs Scale
PTA	Post-traumatic Amnesia
QOL	Quality of life
RRBIS	Royal Rehab Brain Injury Rehabilitation Service
RTW	Return to work
SABIS	Southern Area Brain Injury Service
SCHN	Sydney Children's Health Network (Randwick and Westmead)
STARTTS	Service for Treatment and Rehabilitation of Torture & Trauma Survivors
SWBIRS	South West Brain Injury Rehabilitation Service
TBI	Traumatic brain injury
TLP	Transitional Living Program/Unit
WBIRS	Westmead Brain Injury Rehabilitation Service
WeeFIM	Functional Independence Measure for Children
WHO	World Health Organization

## Abbreviations and glossary

**BIRP case management:** A specific rehabilitation service delivered by clinicians employed as case managers in the BIRP to work collaboratively with clients following admission to BIRP services, their families, the rehabilitation team and others during recovery, resettlement and social reintegration.

**BIRP case manager/s:** Clinicians employed in the BIRP network with specific case management duties.

**BIRS/BIRU/BIS:** Titles of the BIRP services at various NSW locations.

**Case Management Society of Australia (CMSA) key definitions** are consistent with BIRP case management services and include:

- Assessment:** The result of a process to understand the needs and desires of a client in the context of the eligibility requirement for programs.
- Care plan:** The document /outcome of the care planning process. May also include the action plan.
- Care planning:** Processes to outline how the issues identified in an assessment or review of client needs are to be best managed. Involves balancing competing needs, and assisting consumers to come to decisions that are appropriate to their needs, wishes, values and circumstances.
- Coordination:** An action of the case manager that results in the sequencing and delivery of services and resources in an appropriate and timely manner.
- Evaluation:** A process of comparing actual outcomes and processes with expected outcomes.
- Goal:** A statement developed with (and understood by) the client that succinctly describes the intended outcomes from identified needs.
- Outcomes:** The result of an individual action or series of actions undertaken by the case manager and the client towards achievement of a goal.
- Planning:** The process of formulating a scheme or program to meet the outcomes described within goals.
- Program:** The particular case management service the agency provides.
- Review:** A part of the case management process requiring the case manager to examine progress towards achieving client goals with a view to amendments or improvements.

**Client/person/patient:** A child, young person (adolescent) or adult of working age (usually 16–65 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. Client /patient/person are interchangeable when prefacing needs and centred goal planning as phrases. Needs are identified in a collaborative process with case managers and form the basis of rehabilitation planning to achieve personally relevant goals..

**Families (and its derivatives):** Direct and extended family members (not necessarily by marriage) and others who are significant in the life of the client, and may include unpaid care providers. Families are important members of the rehabilitation team and can be direct recipients of BIRP services.

**Local health districts (LHDs):** Currently, public health service funding in NSW is allocated to LHDs for providing health services in a wide range of settings, from primary care posts in the remote outback to metropolitan tertiary health centres. 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. Eight other LHDs cover the greater Sydney metropolitan regions, and seven cover rural and regional NSW.

BIRP services operate from 11 of these 17 LHDs for children, young people and adults under 65 years with traumatic brain injury (TBI)/ acquired brain injury (ABI) living in NSW.

**Young person:** This encompasses a mix of different definitions in paediatrics and includes terms such as adolescent, young adult and teenager.

# Section 1

## Background

The process of determining the NSW Brain Injury Rehabilitation Program (BIRP) model of case management required a review of clinical practice. A working group commenced in 2007.

This document acknowledges the work of all involved from the BIRP case management service network over a number of years.

A survey tool (Appendix 1) was developed to assist in understanding key factors for case management in BIRPs. Information on the model of case management involving seven adult BIRPs was presented in an Internal Report to the BIRD executive in August 2010 and, in recognition that case management is a core element of both adult and paediatric BIRP intervention, a steering committee was subsequently convened. The BIRD steering committee engaged with all 15 adult and paediatric BIRP services to implement the key recommendations of the Internal Report and to finalise documentation of the BIRP model of case management.

### 1.1 Service context for BIRP case management

The BIRP provides the organisational framework for case management. Organisation and service background is provided in Appendix 2.

Rehabilitation aims to improve function and reduce activity limitations and participation restrictions using a client-centred and goal-directed approach. People admitted to specialist rehabilitation services following brain injury tend to be younger, healthier and have more complex needs than those admitted to general rehabilitation services. To meet ongoing cognitive and psychological needs, specialised rehabilitation is provided for the individual and the family as an integrated continuum from injury to recovery and social participation, sometimes over many years. This is a dynamic process that needs to adapt to how the person's

brain injury impacts on the individual and their everyday living, to supporting the individual in all aspects of their 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 the role of specialised brain injury rehabilitation services. BIRP case management is a specific intervention delivered by clinicians employed as case managers in the BIRP to work collaboratively with clients, families, the rehabilitation team and other government, non-government and private agencies during recovery, community resettlement and social participation.

BIRP case management is an integral component of the specialised BIRP rehabilitation team approach required to manage the complexity of recovery and rehabilitation after a severe brain injury. The child, young person or adult may be left with lifelong disabilities in communication, physical functioning, thinking and behaviour that affect their expectations, hopes, dreams and plans for the future. The potential range and severity of disablement can represent a significant challenge to participating in the normal activities of life and to future engagement with their communities.

A BIRP case manager will develop an extensive understanding of the client and family and can assist in negotiating unfamiliar service systems and issues arising from the impact of the injury on everyday living. BIRP case managers enable clients and families to access support services, liaise with employers, meet insurers' reporting requirements and submit requests for funds, rehabilitation plans and service approvals.

While BIRP case managers may have different titles (e.g. rehabilitation case manager/clinician, coordinator), they all do similar work providing the range of clinical interventions involved in the BIRP model of case management.

## 1.2 Recent research and evaluation of the needs of people with severe brain injury

Over the past decade, the BIRD has built a strong platform to inform future developments by conducting evaluation and research to provide evidence of needs and service delivery gaps. Five important pieces of work have included:

1. developing a state-wide data collection system that now allows annual reporting of network activity from adult and paediatric BIRPs
2. developing the capacity to address statewide service priorities (e.g. health service and clinical areas of need)
3. establishing network processes to identify and introduce outcome measures
4. providing initial descriptions of service delivery pathways
5. undertaking preliminary work to benchmark inpatient adult BIRP services with the United States TBI Model Systems Program<sup>1</sup>, regarded as international best practice in brain injury rehabilitation, and a private rehabilitation provider in Victoria.

In addition, project work has been undertaken to build understanding of unmet needs and service delivery outcomes. Recent BIRD reports involving the BIRP network include:

Diagnostic report: A review of the NSW Brain Injury Rehabilitation Program model of care (BIRD, ACI 2014).<sup>2</sup>

The investigation of vocational participation for people with TBI in NSW (2013) McRae, P., Simpson, G.K., Hallab, L., Kent, G., Strettles, B. and Mair, S.<sup>3</sup>

The BIRD annual reports of BIRP activity.<sup>4</sup>

Adult and paediatric challenging behaviours following TBI: (Sabaz, M. 2012;<sup>5</sup> Sabaz, M., 2012<sup>6</sup>)

ABI service delivery in rural and remote NSW (Mitsch, 2011;<sup>7</sup> Mitsch, Curtin, Badge, 2014<sup>8</sup>)

Transitional Living Program (TLP) evaluation report: Clinical outcomes 2009 – 2011 (Internal BIRD report, H. Badge, 2015<sup>9</sup>) and related workshop to identify clinical priorities for service development.

## 1.3 Service delivery types

BIRP case management provides a direct clinical service to clients and families. The BIRP case management survey (Appendix 1: BIRP case management survey) assisted in defining the type of BIRP service delivery for case management that can be used for comparison to other types of case management, e.g., corporate case management. However, the five types of case management service delivery described by Davies (1994)<sup>10</sup> were found to be the most relevant framework. Importantly, the service delivery type described by Davies includes a direct type of service delivery which was the only type found that has a role in working directly with the client plus aspects of the other four types of service delivery. The other four service delivery types are:

- i. Case monitoring (coordination model):
  - assessment, monitoring, referral and coordination only
- ii. Brokerage (support options):
  - assessment, sub-contracting services, monitoring outcomes
- iii. Advocacy:
  - assessment, advocating for services, monitoring outcomes
- iv. Managerial:
  - reviewing assessment and management plans submitted by others, authorising expenditure, monitoring costs.

## 1.4 Service delivery approach

The service delivery approach across BIRP community teams was initially determined by the different ways in which BIRP services were established, funded and located. BIRPs developed separately with a mix of team configurations influenced by budgets, local governance and BIRP locations.

To clarify the service delivery approach of BIRP community teams, the following descriptors were utilised:

- Multidisciplinary: Some staff specialise in case management while others have solely therapy roles.
- Interdisciplinary: All staff provide case management and have their own professional roles.
- Trans-disciplinary: All staff provide case management and undertake a range of therapy roles.
- Case management only.

## 1.5 Scope of BIRP case management

The BIRP provides an innovative, participation-based contextual approach to community rehabilitation that combines the delivery of therapy/medical services and concurrent clinical case management. BIRPs aim to provide adult and paediatric services to all of NSW so there are clinician roles and clinics that cross LHD boundaries.

Not all people with TBI living in NSW have access to specialised brain injury community rehabilitation services in the LHD in which they live. Equity of access issues occur for Far West NSW, some rural and remote clients and particularly for paediatric clients and families (e.g., in the Illawarra /Shoalhaven region).

The scope of BIRP case management is the extent to which it is combined or separated from community rehabilitation therapy services within the same BIRP. Dubbo BIRP and Northern BIRS do not include paediatric case managers or specialist adult and paediatric multidisciplinary clinicians in their teams.

The lack of local access to specialised brain injury rehabilitation medical and therapy services may require families to return to metropolitan hospitals to access the necessary services and support. This can be a barrier to continuing involvement with specialist services that may limit recovery and individual outcomes and increase the burden on families. The three metropolitan-based paediatric BIRPs, in particular, continue to work intensively with a significant proportion of children and families following discharge as much-needed specialist services in their local LHD cannot be located for community reintegration, review at key developmental stages, and long-term support and follow-up.

The BIRP service delivery approach has different team configurations operating across adult and paediatric services for rural and metropolitan community teams. See Table 1 for a description of the adult and paediatric team configurations for the BIRP service delivery approach. Currently, there are no trans-disciplinary BIRP teams providing a mix of case management plus a range of therapy roles.

In adult and paediatric case management-only teams, limited or no access to specialised multidisciplinary brain injury community rehabilitation services means that private/public general rehabilitation and education resources need to be sourced. The case management-only model can be a barrier to timely hospital discharge as a lack of discipline-specific clinicians locally may require the client to stay in hospital so they can access the range of services necessary to achieve further recovery and rehabilitation goals before returning to their local community.

Participants in insurer-funded schemes may have access to local private clinicians but often need metropolitan-based clinicians to travel to them. This can cause difficulties for clients and their families receiving the right support at the right time. External service providers (public or private) can be incorporated into the client management team depending on the goals and needs of BIRP clients to facilitate an integrated whole of person approach. Additional BIRP case management services may be provided to clients and families in rural locations when access to therapy is limited or not available.

Table 1: Adult team configuration

Multidisciplinary	Some staff specialise in case management while other team members have solely therapy roles — Liverpool BIRU (LBIRU)	Liverpool BIRU (LBIRU); Royal Rehab BIRS, Ryde; SCHN (Randwick and Westmead); Westmead BIRS*
Interdisciplinary	All staff provide a mix of case management and their own therapy roles	Hunter BIS (HBIS); Mid-West BIRP (MWBIRP); Mid North Coast BIRS (MNCBIRS); New England BIRS (NEBIRS); Illawarra BIS (IBIS); South West BIRS (SWBIRS); Kaleidoscope PBIRT; Southern Area BIS (SABIS)
Trans-disciplinary:	All staff provide a mix of case management and a range of therapy roles	Adult case management teams at Dubbo BIRP and Northern BIRS
Case management #	No discipline-specific roles available	Paediatric case manager at IBIS; MNCBIRS; NEBIRS; MWBIRP; SABIS

\*Westmead BIRS operate two separate teams which work closely together for case management and therapy services

## Paediatric services

Specialised paediatric rehabilitation service delivery varies in approach and not all paediatric clients living in NSW have access to specialised ABI paediatric community rehabilitation services in the LHDs in which they live. The three metropolitan paediatric services located in Newcastle, Randwick and Westmead provide a continuum of specialised rehabilitation care from trauma hospital admission following injury to discharge, community resettlement and long-term follow-up. See Table 2 for a description of the team configuration for each paediatric BIRP service delivery approach.

There is a lack of a network of non-metropolitan brain injury rehabilitation paediatric services, which has resulted in equity of access issues in the majority of rural NSW.

Table 2: Paediatric team configuration

Multidisciplinary	Teams are multidisciplinary across inpatient and community settings and include BIRP case managers	Sydney Children's Hospital Network Randwick and Westmead; Kaleidoscope BIRP, Hunter
Interdisciplinary	A dedicated paediatric team consisting of BIRP case managers and therapy staff co-located with the adult BIRP	SWBIRS
Case management #	Specialised ABI /TBI paediatric coordinators providing BIRP case management and co-located with their adult BIRP service	IBIS; MNC BIRS; NEBIRS; MWBIRP; Southern Area Brain Injury Service (SABIS)

#In case management-only teams, there is limited or no access to specialised brain injury community rehabilitation medical and therapy staff so private/public general rehabilitation options need to be sourced. Participants in insurer-funded schemes may have access to local private clinicians or metropolitan-based clinicians who are able to travel to the client. External service providers (public or private) where available can be incorporated into the client management team depending on the goals, needs, client resources and access to local health and community services or insurer-funded services. Additional BIRP case management services may be provided in the absence of needed clinicians.

The case management-only model is a barrier to timely hospital discharge while further recovery is achieved to compensate for a lack of local services. The lack of local access to specialist medical and therapy services requires families to return to metropolitan hospitals to access the services they need to manage recovery, community resettlement and social participation following severe TBI.

## 1.6 Clinical pathways

Clinical pathways were initially referred to as care pathways and used for describing discrete rehabilitation functions within the BIRP continuum. BIRP clinical pathways reflect different characteristics of clients who have differing rehabilitation needs and service demands. The clinical pathways in different BIRP settings of care, including community and TLPs, are responsive to different individual needs and can be accessed at different times post-injury. The concept of distinct BIRP clinical pathways was first identified in 2006 as part of the TLP Project (Hopman, K. unpublished<sup>11</sup>) when three care pathways were identified. These have subsequently been expanded to six, with some overlap with community rehabilitation services and case management.

Routine evaluation of client outcomes from different clinical pathways has demonstrated differences in terms of client and injury characteristics, service needs and intensity, length of stay, rehabilitation goals and outcomes.

Clinical pathways specific to adult and paediatric community-based clients are in various stages of development. It is hoped that these will enhance the ability to evaluate outcomes across the BIRP rehabilitation continuum and the demands and outcomes from community services. They are important to help understand some of the reasons underlying varying demands on case management for individual clinicians, teams and the BIRP network. They provide a link between the nature and extent of impairments/disability and the related service needs and utilisation as people recover from their injuries.

The BIRP clinical pathways are different to the idea of standardised 'care pathways' that aim to 'reduce variation and adverse events, and increase the quality and efficiency of care'.<sup>12</sup> There is scope in future to incorporate some of the principles of these care pathways, such as more clearly defining evidence-based interventions and triggers for transition through each setting of care.

# Section 2

## Literature review

Evaluating case management outcomes is difficult. The lack of consensus or discussion on approaches to evaluating the outcomes from case management reflects the embryonic state of research regarding brain injury case management.

A two-stage approach to the literature review was required. Firstly, a literature review was completed to identify literature from other health conditions, including dementia and psychiatric conditions. This review identified the parameters for outcome measurement (See Appendix 9.3.1; Table 3) and assisted with survey development.

A second literature review that aimed to identify best-practice models of community-based rehabilitation was also completed, with a particular aim of identifying case management approaches consistent with the scope and objectives of the BIRP (See Appendix 9.3.2; Table 4).

### 2.1 Identifying best-practice models

#### 2.1.1 Method and results

It is acknowledged that there is case management-related literature in community mental health (Australia); child welfare and protection (USA); and community nursing (UK). However, the focus of the literature review conducted in 2010 and updated in 2013 was specific to case management and TBI.

Databases searched were CINAHL and Psych Info. The search term 'case management' was crossed with terms for 'TBI' (brain injury, traumatic brain injury, head injuries). Citations were accepted if they:

1. addressed TBI
2. were published between 1985-2013
3. published in peer-reviewed journals, book chapters or books
4. applied to people aged between 0-65 years.

Extending the search terms for 'case management' and 'neurorehabilitation' did not result in any further relevant articles being added to the case management and TBI literature review.

The search found that over the past 28 years, only 10 items that sought to evaluate the efficacy of case management in improving rehabilitation outcomes for people with TBI have been published (Appendix 9; Table 2).

- Nine studies focused on adults, one on paediatric ABI (that included TBI).
- The studies were heterogeneous.
  - Two studies were experimental.
  - One study was a descriptive case series.
  - Four studies surveyed/interviewed brain injury staff (case manager training needs; case manager role and activity).
  - Three non-empirical studies, including two that proposed models of case management and one that provided a general overview of case management.
- Three were from the UK, four from the USA and three from Australia.
- Only two articles on case management and TBI have been published over the past five years.
- Case management was rarely defined in the articles. Wood (1995)<sup>13</sup> was one exception, drawing upon the definition proposed by the Case Management Society of America.
- Reflecting the observation of many, case management varied considerably depending upon the organisational context.
- In terms of the rehabilitation continuum, studies focused on an acute hospital setting and inpatient rehabilitation, as well as longer-term community integration and participation.

- Some studies proposed a case management service that provided intervention along the whole continuum of recovery, from admission to hospital through to longer-term community resettlement.
- Roles in case management included assessment, planning, coordination, establishing a working alliance, identification of services/resources, devising rehabilitation plans, referrals, coordination liaison, monitoring, information provision, informal counselling, provision of family support, cost management and efficiency.
- Sample sizes for the two group studies were large, but the researchers had difficulty identifying a matching control group and employed non-randomised designs.
  - One study surveyed case managers employed to improve rehabilitation service delivery in acute health settings in the UK.
  - One study surveyed a case management model of substance abuse treatment for community-based clients in the USA.
- The two group studies used a range of measures to evaluate outcomes.
  - The US study employed two impairment-based measures (non-convulsive status epilepticus [NCSE], addiction severity index [ASI]), one measure of community integration (community integration questionnaire [CIQ]) and three Quality of Life (QOL) measures.
  - The UK study collected data on a wide range of variables including service-related variables as well as impairment (e.g. neuro-physical impairment), functional (e.g., Disability Rating Scale [DRS] and return-to-work [RTW]) participation variables.
- Three of the four studies that surveyed staff employed purpose-designed measures, while one study design was qualitative, utilising semi-structured interviews.
  - One study surveyed the training needs of brain injury case managers.
  - Two studies surveyed the roles of ABI paediatric case managers.
- Neither of the intervention studies found that case management made any significant differences to the outcomes for people with TBI or their families.

## 2.1.2 Conclusions

A number of conclusions can be drawn from the articles identified in this brief best-practice review.

- The published studies have limited applicability to the BIRP.
- The conclusions of a systematic review of rehabilitation practice for TBI<sup>14</sup> - that 'there have been very few studies on the effectiveness of case management' and that 'there is no clear evidence that case management is effective with survivors of TBI and their families, but neither is there clear evidence that it is ineffective... warrants further research to resolve the question' - are still pertinent more than a decade later.
- There is a difference between case management deployed to compensate for deficiencies in, or the absence of, needed services (e.g. trying to make up for the lack of specialist brain injury rehabilitation units) and case management that is deployed to further promote recovery within the context of an adequate service system.
- Case management often operates from the difficult position of meeting the needs of at least two key stakeholders – the clients and the payers (insurers/funders) – and this creates a tension in defining optimal outcomes.
- The primary outcomes of good case management are comprehensive and efficient access to services. However, the outcome measures selected to evaluate case management are often impairment- and function-oriented, which are secondary, arising from the input of the services that the person has accessed. Outcomes for the evaluation of case management need to be more clearly defined and directly related to the primary roles and inputs of case management.
- One book on brain injury case management has been published<sup>15</sup>. However, it is very specific to the UK service system and makes limited use of the ABI literature.

# Section 3

## Case management in the BIRP

Case management is a collaborative process involving the coordination, rehabilitation, care and support of people with complex clinical needs following a TBI or ABI. The aims are to facilitate clients' independence and improve their QOL. This provides a framework for evaluation of client outcomes and the effectiveness and quality of services.

BIRP case management provides a direct clinical service to clients and families. In this model, a large percentage of the case management team's time is allocated to working alongside the client and family and in client-related activities.

### 3.1 Principles

BIRP case management services developed locally from the ground up rather than having a statewide model imposed from the top down. It has now been ascertained that there is a high degree of homogeneity underpinning the principles of BIRP case management across adult and paediatric BIRP teams. The principles are consistent with BIRP organisational principles and are listed below:

#### 1. Needs-driven

Intervention is not dependent on initial injury severity, but rather on the nature and degree of disablement and impact on the person. BIRP case management is provided in a flexible manner and the duration of intervention is based on continuing need rather than having a pre-determined time-limited program.

#### 2. Goal-directed

Social rehabilitation is multidimensional, with goals representing the sum of client-expressed needs, assessment and third party-identified needs.

#### 3. Community-based

Where possible, intervention is contextually based and conducted within the environment in which the person lives, learns, plays, works and socialises. The approach is holistic and is informed by biomedical, neuropsychological, neurobehavioural and community participation paradigms involving a range of medical, clinical and support staff operating together to maximise client outcomes.

#### 4. Participation-focused

Outcomes represent the product of the interaction between individuals and their social, physical, service, attitudinal and political environment.

#### 5. Involves family

Families are recognised as important members of the rehabilitation team, and can influence rehabilitation and community outcomes when providing emotional, practical and social support. BIRP case managers provide families with education and support to maximise client outcomes and sustain positive family relationships.

### 3.2 Aims

BIRP case management aims to:

- engage with complex clients admitted to BIRP services following brain injury and their families to provide case management interventions
- encourage, educate and support people to reclaim decision-making, responsibility and control over their lives following brain injury
- partner with clients and families in the rehabilitation process
- work collaboratively with all involved for integrated decision-making and planning to achieve goals identified with the client
- incorporate where possible evidence-based best practice into everyday situations with reference to international best practice.

### 3.3 Definition

The definition for case management in the BIRP is as follows.

BIRP case management is a direct clinical intervention, primarily for children, young people and adults of working age who have had a moderate-to-extremely severe TBI and their families. The various elements of BIRP case management practices are integrated and provided according to individual goals and needs with the involvement of relevant others to ensure that the required rehabilitation services and support are available, accessible and coordinated.

BIRP case management is contextually based and has the flexibility to provide services in the home, school, work and community environments. This definition of BIRP case management was developed collaboratively as there is no specific definition of brain injury rehabilitation case management in the literature. Information relevant to the development of this definition included:

- a description by Scheinberg et al (2005)<sup>16</sup> when reporting the results of a survey of paediatric ABI case managers
- the 2006 definition provided by the NSW Rehabilitation case manager's Network
- key factors obtained from surveying adult and paediatric BIRP case managers in 2010 and 2012.

### 3.4 Components / Core elements

A specially developed survey (Appendix 9.1.2) was completed by BIRP community staff to assist with describing case management and determining commonalities across teams to assist with model development. It was determined that BIRP case management:

- Provides a comprehensive, whole-of-life approach that is enduring and not time-limited.
- Is a direct service model with the majority of tasks undertaken by the BIRP case manager.
- Has a clinical approach to the case management process and not an administrative management role, so the focus is working directly with clients and families. Decision-making is client-led not clinician led. This item in the survey responses was the most tightly grouped item, indicating that each of the services shares a similar view.
- Is a clinical process where the starting point is establishing the needs, wishes, and dreams of the person and is not service-led (the process of identifying which services a client is eligible for, and then referring the client to those services).
- Has no significant differences between metropolitan and non-metropolitan case management practices.

The identified consistency in approaches to the process of BIRP case management assisted in the development of a matrix of 10 core elements or tasks. These 10 tasks were further reviewed by the steering committee with involvement of all BIRP services, to validate the components of BIRP case management and to define the core elements. Importantly, the components/core elements have developed out of clinical experience in responding to the identified needs of people with ABI over many years and operate within a contextually-based rehabilitation approach. BIRP case managers allocate time across all 10 components/core elements, although this varies with workload and organisational demands.

### 3.4.1 BIRP case management components

**There are 10 primary components or core elements of BIRP case management intervention.**

#### **1. Assessment**

Complete holistic assessments at referral and subsequent key points.

#### **2. Goal setting and support planning**

Develop client-centred, needs-based goals using clinical reasoning and in liaison with all relevant stakeholders.

#### **3. Referral and liaison**

Manage access to, and support for, non-BIRP services.

#### **4. Monitoring and reviewing**

Use an interactive process for the purpose of tracking client status during rehabilitation.

#### **5. Individual client work**

Use clinical knowledge and expertise to develop support structures that maximise participation by building individual capacity in combination with environmental supports.

#### **6. Advocacy**

Undertake individual and systemic advocacy to achieve equity of access to existing resources.

#### **7. Coordination**

Manage the involvement of multiple stakeholders to work together as a team.

#### **8. Support of family and social networks**

Work collaboratively with families and social networks to support clients in community living and social participation.

#### **9. Education**

Provide needs-based education to individuals, families/social networks and service systems.

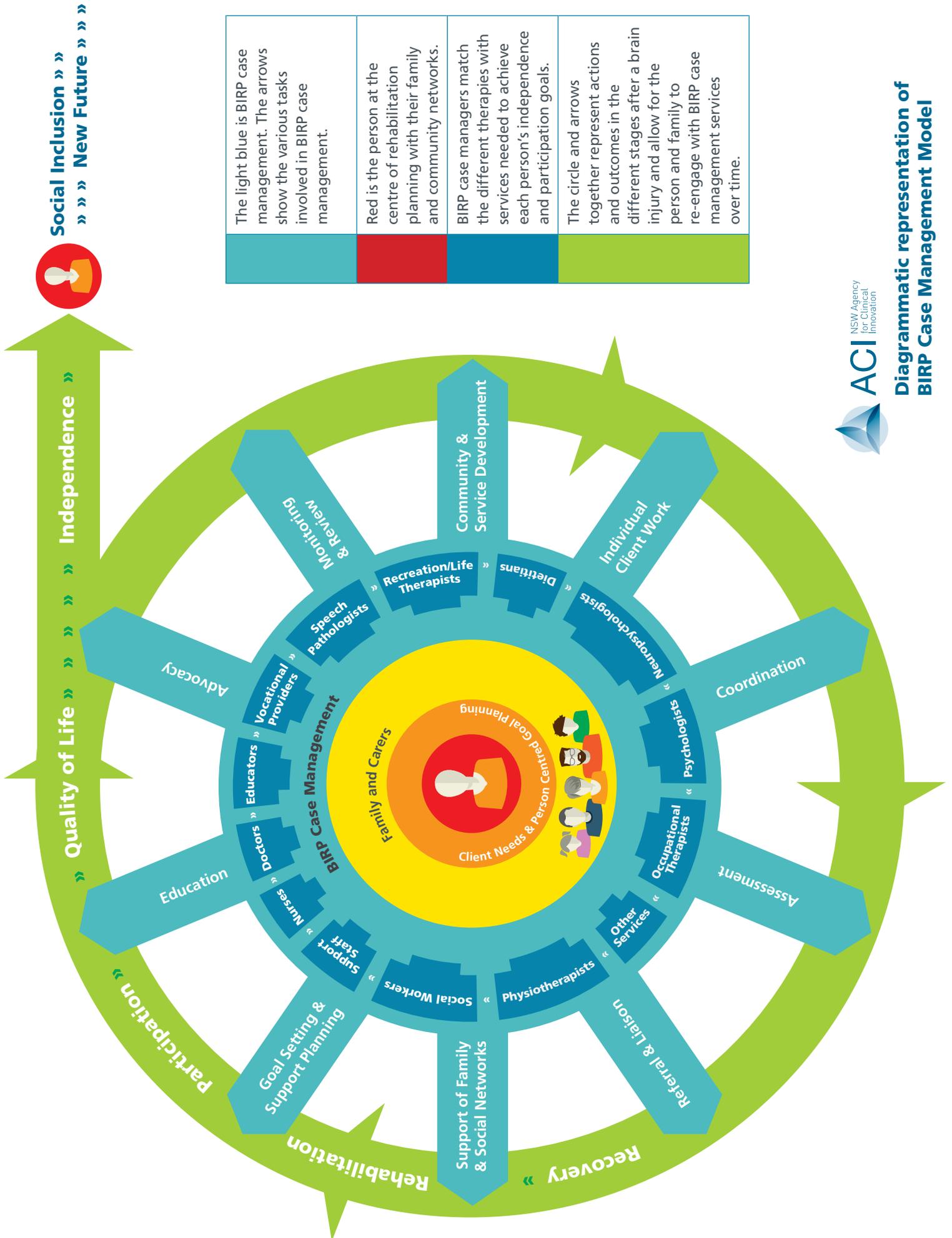
#### **10. Community and service development**

Investigate and influence policies and practices to ensure that service systems are responsive to individual and family needs.

In addition, a number of key indirect client tasks that are specific to the operation of BIRP case management services and additional to the core elements were identified. These include client, family and team meetings, insurer plans, report writing, audits, gathering statistics, professional development and organisational tasks. These were not classified as a component/core element of practice, although each of these tasks, separately and together, can be time-consuming. Travel was an additional and important consideration for maintaining a contextually-based rehabilitation approach.

In combination with the BIRP direct service model of case management these core elements of practice comprise an expansive definition of case management in comparison with the international literature and national benchmarks.

### 3.4.2 Diagrammatic representation of BIRP case management



	The light blue is BIRP case management. The arrows show the various tasks involved in BIRP case management.
	Red is the person at the centre of rehabilitation planning with their family and community networks.
	BIRP case managers match the different therapies with services needed to achieve each person's independence and participation goals.
	The circle and arrows together represent actions and outcomes in the different stages after a brain injury and allow for the person and family to re-engage with BIRP case management services over time.



**Diagrammatic representation of BIRP Case Management Model**

### 3.5 Comparison with national benchmarks

Having developed a definition and identified the components/core practice elements for the model of BIRP case management, it was then important to review how comprehensive or restrictive the model appeared within the broader Australian health, rehabilitation, disability and professional contexts.

The Case Management Society of Australia (CMSA) National Standards of Practice for Case Management provided the initial external reference point chosen to benchmark the BIRP model of case management. The six core standards from 2006 were replaced with four core standards following a review by Marfleet, et al (2013).<sup>17</sup>

The four CSMA National Standards are now:

- i. Standard One: Case Identification (screening) and Assessment
- ii. Standard Two: Planning
- iii. Standard Three: Monitoring
- iv. Standard Four: Evaluation and Outcomes.

These national standards are supported by a National Code of Ethics for Case Management<sup>18</sup> and a self-assessment framework. In addition,

- the practice principles have been more clearly delineated and better support the case management framework
- the CMSA standards now reflect a more client-centred collaborative planning approach that includes identification of needs (previously a separate standard)
- the CMSA Monitoring standard now reflects a more circular review process
- the CMSA standards have been revised from service-related evaluation to now share a client outcome focus and better align with BIRP case management by separating out the practice of case management from the evaluation of client outcomes.

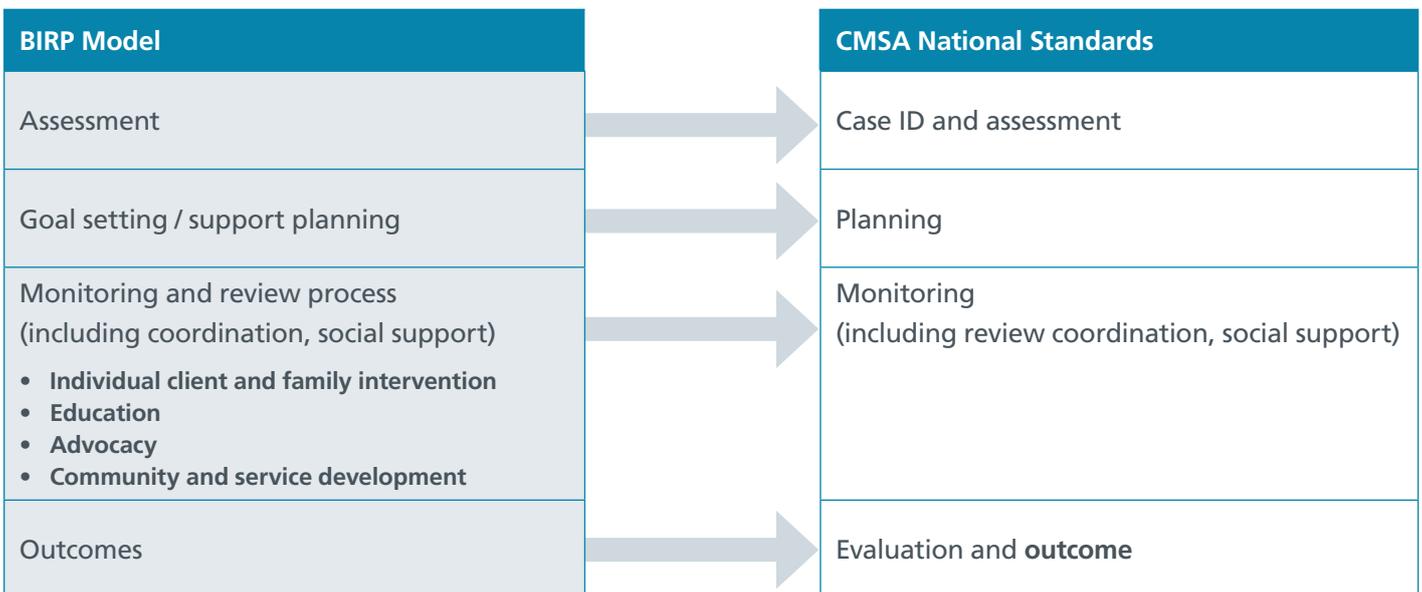


Figure 1: Benchmarked BIRP case management core elements

The BIRP case management model incorporates all four of the revised CMSA National Standards of Practice. An additional four core standards that support the specialised brain injury rehabilitation approach, particularly in areas of individual and family support, education, and stronger individual and systems advocacy roles. Some of these additional standards may reflect a continuing lack of required service infrastructures and access to the right service at the right time to support people with brain injury and their families.

In summary, the additional standards reflect the specialised rehabilitation needs of the client population and the development of clinical practices to achieve recovery, rehabilitation and social participation goals. The client-centred goal-planning approach used in the BIRP services supports a practical framework for BIRP case managers to provide integrated care that exceeds the national standards.

# Section 4

## The BIRP case management process

Figure 2 illustrates the clinical pathway to better understand the BIRP case management processes. The different elements in the process of BIRP case management are then provided.

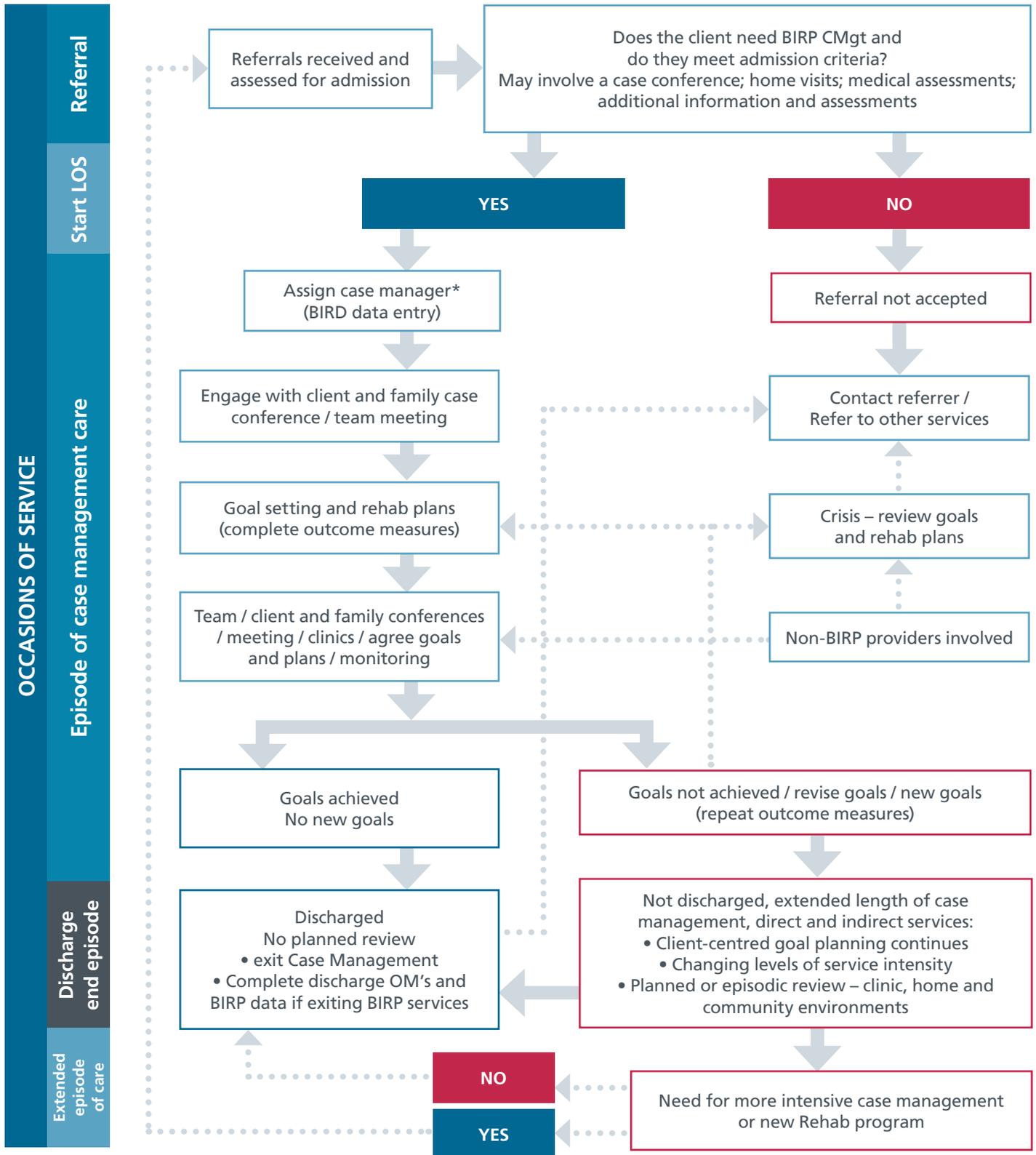


Figure 2: BIRP case management clinical pathway (NB. LOS = length of stay, rehab = rehabilitation)

\*Can be assigned at a later stage

## 4.1 Referral for BIRP case management

The BIRP case management start date is when the referral is accepted. This date may be the same or different from the date the referral is received. Referral information may be insufficient to determine if the person meets the admission criteria and case managers can be involved in obtaining additional information (including meeting with the client/significant others) to determine eligibility.

Referrals for BIRP case management are primarily received as a continuum of care from hospital to home, although they can be made earlier or later. Community referrals are commonly received from regional hospitals; referrals from general practitioners and self-/family referrals are also common.

Clients known to the service can be re-admitted for BIRP case management (and other BIRP services) when circumstances change. For the client and family, contacting a familiar BIRP service or BIRP case manager can minimise the disruption experienced when presenting to a new service where the background and circumstances are not known and understood.

Clients referred for consultation can be accepted for a reduced program involving assessment and planning to support a different agency working with a person with ABI/TBI (e.g. mental health services, disability service providers).

Some BIRPs may provide privately funded case management services for local clients who do not meet the BIRP eligibility criteria (e.g. non-TBI clients, clients with a spinal cord injury). These clients are managed separately to the BIRP case management and service pathways.

## 4.2 BIRP case management acceptance criteria

BIRP case management is provided to clients who meet admission criteria for the BIRP services. BIRP case management criteria are listed below:

- evidence of a brain injury
- severity of brain injury
- the injury occurs any time after birth and before 65 years of age
- changes in the person's communication, physical functioning, cognition and behaviour and the impact of these on everyday living and community participation
- the need for specialised brain injury rehabilitation and the involvement of multiple providers evidenced by goal complexity
- complex social circumstances
- management of injury insurance.

Accepting a client for BIRP case management is usually decided at regular team meetings. Including case management in the suite of brain injury rehabilitation services offered to clients and their families and the extent of involvement will depend on the individual, their circumstances and whether the needs are best managed by a BIRP case manager.

BIRP case managers also work with case management providers from other agencies when the client is:

- unable to participate in the brain injury rehabilitation program due to comorbidities
- able to access privately funded case management services
- wanting an alternative provider
- able to access non-specialist services as they can provide the level of case management support required
- not able to access specialist brain injury rehabilitation case management services locally (e.g. distance)
- not needing specialised BIRP case management as the focus of client goals changes (e.g. living with disability, health issues not related to the brain injury).

In these circumstances the BIRP case manager has a secondary role and does not provide direct client and family interventions. Generally, the involvement will focus on building capacity, education and support to consider brain injury impairments and consequences when working with the client and family and for planning and service delivery.

### 4.3 Engagement of the client and family

Engagement of the client, their family and 'significant people' (e.g. carers, friends, relatives, teachers, aides, coaches, etc.) in the rehabilitation process is seen as a key element of effective, appropriate and meaningful case management.

It is essential that the client, family and significant people have trust in the BIRP case manager and that they feel confident that the needs, hopes, dreams and wishes of the client are actively considered for inclusion in the plans for their future. The BIRP case manager must therefore be highly sensitive to the need to not only engage the client, but also their relevant significant others, in a 'team approach' for rehabilitation, while concurrently supporting the client to gain appropriate control over their own future.

### 4.4 Intensity of service

BIRP case management can vary in intensity depending on what is happening in the person's life. BIRP case management often starts when the person is being discharged from the inpatient rehabilitation ward or acute hospital setting but can start earlier or later in the recovery and rehabilitation continuum.

### 4.5 Responding to a crisis

The BIRP does not provide a crisis case management service. However, BIRP case managers can be involved in providing the client and family with the information they need to access appropriate services in response to a crisis.

Following a crisis, the goals of the client, involvement of the BIRP case manager and configuration of the treatment/therapy team may change so reassessment and review will be required. The extent of change to rehabilitation planning will depend on the type and outcome of the crisis that arises and impact for the client, family and service providers.

### 4.6 Goal-directed rehabilitation planning and monitoring

BIRP case managers utilise a client-directed goal planning framework for assessing abilities and developing, monitoring, reviewing and evaluating goals. BIRP case managers work with clients, their families and social network to facilitate the involvement of the rehabilitation team and other providers in achieving agreed client goals. BIRP case managers often develop rehabilitation plans, liaise with funders and advocate for clients in the broader compensable injury management context. This is a circular process of setting goals, monitoring and review.

Goal-setting has been described as 'the formal process whereby a rehabilitation professional or team; together with the patient and/or their family negotiate goals'.<sup>19</sup>

Goal-setting includes the actions of:

- identifying goals with clients/parents of children and the rehabilitation team
- establishing steps
- designing an action plan
- monitoring progress and reviewing goals
- evaluating goal achievement.

These actions are consistent with the use of goal-setting in the literature, although no papers specifically define these inclusions.

There are many benefits to setting client-centred goals to direct rehabilitation intervention. High-quality goals can be useful to support client participation, planning within a team context and to gain approval when funding for services is requested. Goal-setting helps empower clients and ensures that rehabilitation is targeted to address the priorities identified by the client. Engaging the client and the rehabilitation team in goal-setting is useful for clinicians and services as they can ensure individual team members work towards the same goals, are responsive to changes in individual skills and needs, inform treatment planning and manage communication about client progress to support planning, service access and funding.

## 4.7 Communication

The key responsibility of the BIRP case manager is to establish and maintain relationships through excellent communication skills. The client is central to all communication and BIRP case managers have a broad responsibility for formal and informal communication with a range of people and organisations.

The BIRP case manager will maintain professional relationships with the client, significant others, team members, service providers, and organisations involved in the client's rehabilitation and care. This may also include communication with authorities that have mandatory reporting requirements, legal representatives, and others such as the Office of the Trustee and Guardian.

Structured and streamlined systems and strategies for keeping the whole team updated appropriately and in a transparent and timely manner support effective communication in the coordination of rehabilitation programs. Communication may be in person, by phone, in conferences and meetings, written reports and letters. Considerable documentation may be required by statutory authorities such as NSW Health, Lifetime Care and Support Authority (LTCSA) and child protection agencies.

BIRP case managers manage personal information in accordance with NSW privacy law and seek consent from the clients and their families, as required. As technology develops, communication strategies with clients and families may include video-conferencing, Telehealth, emails and text messaging consistent with NSW Health policies and practice guidelines.

## 4.8 Involvement of non-BIRP services in rehabilitation planning

The BIRP case manager includes a range of non-BIRP agencies in the rehabilitation planning process to achieve a more person-centred community-focused program. Over time, and as recovery continues, clients move further away from their medically-focused inpatient treatment and engage with local health, disability and community support services.

The BIRP case manager will often be in regular contact with a wide range of non-BIRP health professionals who are also working with their client, and who comprise the rehabilitation team, e.g. general practitioners, treating specialists and private providers, such as physiotherapists, occupational therapists, speech pathologists, clinical psychologists, counsellors, dietitians, dentists, orthotists, chiropractors, personal trainers, exercise physiologists, natural health practitioners (massage, acupuncture, naturopathy), etc.

Involvement of an agency or service will depend on the goals and needs of the client. Common examples include:

- attendant care providers
- public and community housing
- vocational rehabilitation
- disability employment services
- schools, universities, TAFEs and private colleges
- Centrelink
- probation and parole officers
- domestic violence liaison officers
- Legal Aid
- Disability Support Services (e.g. respite and vocational programs)
- financial counsellors and financial managers
- volunteer services
- advocacy services (e.g. Carers NSW, Brain Injury Association of NSW, Multicultural Health & Advocacy services, STARTTS)
- child protection agencies
- child support services (e.g. Brighter Futures)
- Vision Australia
- Office of the Public Trustee & Guardian.

As much as possible, BIRP case managers work collaboratively with these different providers to achieve integrated rehabilitation planning and intervention as well as services and supports for the health and wellbeing of clients and families.

## 4.9 Duration of BIRP case management

BIRP case management is flexible and often required over time to manage continuing recovery, community integration and social participation. The level of intensity and service frequency will vary in response to specific needs.

- The client's psychosocial circumstances may be complex, so there are multiple clinicians and providers engaged with the client.
- It is not easy to transfer clients with complex needs to more appropriate intensive services or long-term case management services when rehabilitation goals have been achieved as they may not be able to connect with the client, are not available or the client refuses, and private case management is not funded.
- The client or family mostly self-manage, but require episodic problem-solving, and so return for additional advice/assistance when needed.
- A review assessment for LTCS participants is required for entry to or exit from the scheme.
- The client is not ready to engage in some rehabilitation activities until they have worked through early adjustment issues or experienced some 'reality' testing.

The length of a BIRP episode of care is reported in BIRD annual reports of activity for all five settings of care. Overall, in the adult BIRP community setting of care about 25% of clients stay less than three months, a further 40% stay between three and 12 months and only about a third will stay more than a year. For the paediatric BIRP community setting of care however, the majority stay more than 12 months with only 25% discharged after less than 12 months. Usually paediatric BIRP clients will remain as continuing clients for many years after the initial injury with, some transitioning to adult BIRP services.

However, the duration of BIRP case management and readmissions for case management are not currently recorded separately from the episode of care. The episode or duration of the BIRP case management service is from the time the person is accepted for, or first receives, BIRP case management services until discharged from BIRP case management. The majority of BIRP case management clients are discharged when rehabilitation goals have been achieved and the person has no new goals requiring specialised BIRP case management intervention. The episode or duration of BIRP case management is not necessarily consistent with the episode of care calculated from the dates of each BIRP admission and discharge, which may start and finish at different times for BIRP case management and different BIRP service settings.

## 4.10 Extended BIRP case management

Long-term specialised case management is often required for clients who have sustained severe TBI to manage developmental and life changes, particularly in the paediatric population, as well as specific issues arising for the client, family or providers in managing everyday problems and concerns.

The paediatric case management model promotes the active engagement of families, so involvement with paediatric BIRP services often continues throughout key developmental stages for children and young people, including managing school changes and educational expectations. This means paediatric BIRP case management may have a length of service of up to 18 years or, in circumstances where tertiary education is an option, even longer, unless a transition to adult services can be successfully completed.

The need for extended BIRP case management is usually identified as a component of goal-setting in response to different client and family circumstances and managed using the same processes as are employed for people with shorter episodes of case management. Client-centred goal planning provides a clear framework for BIRP case management intervention and managing changing needs over extended periods of time. For some paediatric and adult clients the option of transferring extended case management to private providers or disability case management services can be discussed with the client.

Extended case management contact may be at a lesser level of intensity, occur in clinic, or on an episodic or intermittent basis for review or in response to a change in circumstances. In some circumstances, case management may be transferred to an alternative provider to facilitate goal planning that merges the maintenance of rehabilitation gains in everyday practices with the transition to living with disability and changes to life goals arising from brain injury.

The overall aim of extended BIRP case management is to be proactive in preventing the breakdown of the necessary support and services required to maintain rehabilitation goals, community support and social participation activities. This intervention frequently assists in maintaining family and service provider relationships and reduces inappropriate readmission to hospital, homelessness and involvement of the criminal justice system.

## 4.11 Discharge

Clients are usually discharged from BIRP case management when their goals requiring specialist case management intervention have been achieved. Some BIRP clients may be referred to private case managers to continue and maintain current rehabilitation goals or to work on establishing new or adjusted life goals. The BIRP case manager will assist the client's transition to other case management services, when required. Other discharge reasons are consistent with the BIRP service criteria, e.g. refusal to participate (by the client or legal guardian), other issues or barriers (e.g. management of comorbidities, in detention/corrective services facilities) or relocation. In some circumstances, clients may be discharged from BIRP case management, but will continue as an active BIRP client, if remaining in contact with other BIRP team members for different services, e.g. rehabilitation specialist clinics, swallowing review, review of physiotherapy program, education, consultation, liaison and program review with provider agency.

# Section 5

## Factors influencing BIRP case management

There are many factors that influence the provision of BIRP case management services. This section explores case management and the activity of BIRP services, the impact of brain injury and issues affecting service delivery, so that the context in which BIRP case management is provided can be better understood. Common factors include the consequences and complex nature of TBI impairments and associated disability, such as consumer experiences, and the additional issues for:

- children and young people with brain injuries
- those living in rural and remote parts of NSW
- those of Aboriginal and Torres Strait Islander descent.

Other factors influencing BIRP case management include:

- the impact on families and carers
- the impact of geography as a barrier to providing specialist rehabilitation services
- caseload and workload factors
- funding issues.

### 5.1 BIRP activity and case management

Data regarding the caseload seen by BIRP services each year is routinely reported and can be used to monitor work volumes and the characteristics of clients. BIRP services primarily admit people with severe traumatic brain injury. Available data shows that each year over 60% of BIRP admissions over eight years old have a severe TBI determined by the duration of confusion being greater than seven days following impact to the head that is severe enough to cause brain dysfunction. This is termed post-traumatic amnesia (PTA). It is not always possible to measure PTA (e.g. in children under eight years of age; penetrating injury etc.). In these circumstances, severity is clinically determined by a medical/rehabilitation specialist and based on examination, injury history, hospital records, neuroimaging and neuropsychological testing.

Consistently across the NSW network, 80% will be admitted with a TBI and 20% with other types of ABI every year. More than 33% of all people with TBI admitted to BIRP services will have motor vehicle-related trauma and falls are the next most common cause (>20%).

- More than 50% of people with TBI are aged between 17 and 54 years old and a further 41% are 16 years old or under.
- Falls are the most common injury cause for children under 5 years old (more than 30%). This is in contrast to children aged 5-16 years old, where the most common causes of TBI are motor vehicle- and sport-related.

In 2011 there were a total of 3,266 clients receiving BIRP services including:

- 1,609 distinct clients, admitted or discharged in the calendar year
- 1,657 clients, admitted prior to the reporting year and not discharged (continuing clients).

Continuing clients will have a range of injury dates, be involved in different settings of care and receive differing levels of rehabilitation program intensity.

BIRP case management seeks to work collaboratively with clients, families and social networks to achieve positive change and adjustment within a client-directed, goal-based rehabilitation framework. However, case management intervention is not separately recorded for direct client and family intervention and for indirect client-related activities, and this is more fully explained in Section 6.

The types of services engaged in client rehabilitation are wide-ranging. Following a TBI, there are factors related to the injury, the person, the family, the environment and cultural influences to consider, and the variety, range and complexity are unique to each individual.

Key factors for effective case management are listed below.

- Human resources – staff available, experience and skills, client load.
- Access to the right service at the right time for clients and families.
- Where a person lives, access to transport and rural disadvantage will impact on intervention intensity and service types available.
- Finances – increased cost of disability, loss of income, financial obligations (e.g. additional burden for family).
- Insurance – meeting scheme criteria for funding request approvals, delayed and non-approved service requests.
- The influence of cultural factors on the level of understanding about the purpose of rehabilitation.
- Engagement of multiple providers with different levels of understanding of the impact of brain injury for the person, their family, their community.

These factors can influence the outcomes of BIRP case management and achievement of client goals for recovery, community integration and social participation.

## 5.2 The consequences of TBI

The sequelae of TBI commonly include impairments of cognitive function, physical function, social and emotional changes, and behaviour change. No two brain injuries are the same and consequences will be individual to the person and their circumstances.

Clinically, people often find that relationships change; they cannot return to their pre-injury school or employment, or if they do, they are unable to manage change in the classroom or workplace and so cannot sustain employment over time, or need support to manage different learning strategies and social interactions. Others find that they move from being independent, and the person who is a leader or in control, to requiring assistance to make decisions or to carry out daily tasks and even being dependent on others in one or more life domains. Some people will have very limited understanding and awareness of the changes that have occurred to their abilities and subsequently maintain a belief that they can do the same things, creating anger, frustration and inability to understand what went wrong, so they blame others for failure. These problems can be profound and long-term, with personality and behaviour change leading to significant lifestyle effects that flow from neurological and cognitive impairment.

Table 3 provides a summary of common consequences of brain injury.<sup>20,21</sup>

<b>Neurological impairment (motor, sensory and autonomic)</b>	<ul style="list-style-type: none"> <li>• Motor function impairment – coordination, balance, walking, hand function, speech</li> <li>• Sensory loss – taste, touch, hearing, vision, smell</li> <li>• Sleep disturbance – insomnia, fatigue</li> <li>• Medical complications – spasticity, post-traumatic epilepsy, hydrocephalus, heterotopic ossification</li> <li>• Sexual dysfunction</li> </ul>
<b>Cognitive impairment</b>	<ul style="list-style-type: none"> <li>• Memory impairment, difficulty with new learning</li> <li>• Attention and concentration</li> <li>• Reduced speed and flexibility of thought processing</li> <li>• Fatigue</li> <li>• Impaired problem-solving skills</li> <li>• Failure to initiate tasks and inattention to task</li> <li>• Problems in planning, organising and making decisions</li> <li>• Language problems – dysphasia, problems finding words, and impaired reading and writing skills</li> <li>• Impaired judgement and safety awareness</li> </ul>
<b>Personality and behavioural changes</b>	<ul style="list-style-type: none"> <li>• Impaired social and coping skills, reduced self-esteem</li> <li>• Altered emotional control – poor frustration tolerance, poor anger management, aggression, denial and self-centredness</li> <li>• Reduced insight, disinhibition, impulsivity</li> <li>• Perseveration</li> <li>• Psychiatric disorders – anxiety, depression, post-traumatic stress disorder, psychosis</li> <li>• Age-inappropriate behaviour</li> <li>• Inappropriate sexual behaviour</li> <li>• Apathy, amotivational states</li> <li>• Inappropriate speech and verbal outbursts</li> <li>• Difficulty waiting/bolting/absconding</li> <li>• Non-compliance.</li> </ul>
<b>Common lifestyle consequences</b>	<ul style="list-style-type: none"> <li>• Unemployment and financial hardship</li> <li>• Inadequate academic achievement</li> <li>• Lack of transportation alternatives</li> <li>• Inadequate recreational opportunities</li> <li>• Difficulties in maintaining interpersonal relationships, marital breakdown</li> <li>• Loss of pre-injury roles</li> <li>• Loss of independence.</li> </ul>

Table 3: Potential consequences of traumatic brain injury

All of these changes will frequently occur in the context that the person is able to remember who they were before their injury, and the context of changed personal or family expectations.

### 5.2.1 Additional factors for paediatric BIRP clients

While the impairments of ABI sustained in childhood reflect the characteristics of adult ABI in many ways, when skills are undeveloped or immature at the time of injury, the resultant effects may be more global and devastating for children. They occur in the context of, and can disrupt progression through, normal developmental stages<sup>22</sup>. There are important developmental factors that need to be considered when working with children with ABI. Sustaining a brain injury during early life development requires ongoing monitoring, as the very foundations of growth and building blocks of learning are interrupted.

There is a growing body of evidence around the recovery trajectories of children with TBI from the Australian arena. In a study published in 2012, Anderson and colleagues<sup>23</sup> described key factors that impact on the child's function and recovery over 10 years post-injury. While severity of injury was found to be relevant to early outcome, it was less important with time since injury. It was also found that children injured under the age of three years old had worse outcomes than older children. The study demonstrated that environmental and child factors contributed to longer-term recovery, as well as injury factors. In particular, pre-injury adaptive function predicted 10-year adaptive abilities, whereas social and behavioural outcomes were predicted by family function.

In a review of pertinent issues following paediatric TBI, Savage et al (2005)<sup>24</sup> 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 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.

Engagement with paediatric rehabilitation services is often a long-term, continuous relationship. Children and young people may experience a plethora of learning, behavioural, social and developmental issues at any stage of development, but particularly at times of rapid growth and change. These clients will have ongoing or intermittent needs for a variety of therapy and/or medical intervention as they develop and mature. For this reason, clients of paediatric brain injury services may be monitored from the time of their injury until school leaving age, when they have reached a period of relative developmental stability, or where there are no significant needs or goals for specialist rehabilitation intervention. The provision of at least annual medical clinic reviews enables their changing status and needs to be monitored. Ideally, there is at least one primary service that maintains consistent contact with the child/young person.

The families of the child/young person are usually a consistent presence in the BIRP rehabilitation process and their everyday life activities. The effectiveness of family functioning can independently impact on the child's outcome over and above the impact of the severity of the initial injury.<sup>25</sup> Child behavioural and cognitive impairments can adversely affect family life, parental adjustment and familial interactions. This in turn can negatively affect a child's psychological adjustment, even in the face of good cognitive recovery.<sup>26,27</sup>

For these reasons, the model of care for paediatric clients differs from adult models of care in both the duration and longitudinal nature of service delivery. The intensity of service delivery similarly fluctuates more widely than is the case with adults, as periods of intervention intensify at key developmental stages and transition points (e.g. in the early stages of development [0-5] years old, starting kindergarten, transitioning to high school). These key points reflect intense periods of physical, emotional, cognitive and social change and skill development that characterise this relatively short, but significant, stage of life.

### 5.2.2 Additional factors for young people in BIRP services

Normal development is disrupted when brain injury occurs in children and young people. This has a continuing impact as they move through puberty and into adulthood. The very nature of moving into adulthood means that young people will be involved in major transitions during this life stage. Significant transitions for young people include moving from high school into post-school options and from child and youth-focused services (paediatrics) to adult services. As with any transition for people with ABI, early planning is paramount to ensure the best possible outcomes.

To work successfully in the BIRP case management role, an understanding of the developmental stages experienced by young people with TBI is required. This includes understanding identity development, psychosocial development, the relevant brain maturation that occurs during this life phase, physical changes and the importance of developing problem-solving, decision-making and resiliency skills during the transition phase.

The BIRP case manager has a significant role in overseeing these transitions for young people and 'thinking ahead' to proactively plan as much as possible. It is important to provide opportunities for young people to lead their own transition planning and to speak as much as they feel comfortable during the transition, using steps such as:

- speaking about themselves, and for themselves, at any meetings
- planning with the BIRP case manager what they will talk about and how
- creating and using written strategies and roleplay practice.

Often the role of a case manager working with adolescents is focused on finding a way to engage them so that they will actively participate in rehabilitation and knowing when it is appropriate to facilitate independence or re-engage with parents.

Assisting families to support the young person transition to independence is an important role for BIRP case managers. Engaging the young person and their family in identifying new rehabilitation goals and liaising with adult services will facilitate successful transition processes. BIRP case management aims to ensure that transition from high school to post-school options begins as early as possible, often starting during the years 9 and 10. This is done through ongoing work with young people, their families and their schools. In addition, the medical clinic review provides an opportunity for young people to engage with the team and their family to start formal planning for life beyond school – vocational, educational, medical, avocational and social relationships, to support young people to direct their goal planning and take a leading role in decision-making. Where possible, and when available, liaising with ACI Transition Care Network<sup>28</sup> may assist in bridging service gaps for young people with chronic care needs.

### 5.2.3 Additional factors when working with Aboriginal people

The ACI report 'Acquired brain injury rehabilitation service delivery for rural and remote NSW' (2001)<sup>7</sup> identified key factors influencing the engagement of Aboriginal people living in rural and remote NSW with BIRP and non-BIRP services. These projects are important for all BIRP clinicians and case managers providing services to Aboriginal people, especially when visiting Aboriginal communities and liaising with Aboriginal Health Services.

Increased awareness of some key factors in the engagement of Aboriginal people include:

- cultural issues of kinship and connection to community
- understanding when a person experiences a sense of shame (bringing attention to one self) after returning home
- how to build trust relationships when not based in that town/community
- the impact of large distances between rural BIRP workers and an Aboriginal client who lives remote from the service on the delivery of intensive and/or contextual ABI rehabilitation.

Suggested strategies to improve the cultural appropriateness and success of interventions when working with Aboriginal people that were identified in the ACI report include to:

- use public relations strategies to develop trust and engage the local Aboriginal community to build understanding of the importance of specialised brain injury rehabilitation and strategies for everyday living
- target Aboriginal health workers who have good retention rates and community links via open days to champion brain injury awareness and rehabilitation interventions
- use Aboriginal Liaison Officers (ALOs) in each LHD to maximise contact with clients and their families and facilitate positive communication
- site multidisciplinary specialised rehabilitation clinics closer to where clients and their families live
- develop and provide cultural awareness training for BIRP staff that specifically explores the issues relating to perception of brain injury, rehabilitation, the influence of culture and other factors.

#### **5.2.4 Consumer experiences**

The lived experience of the impact of brain injury has been explored to understand the perception of individuals following brain injury and how they understand and adapt to the impact of the injury.

The patient experience assists health workers to increase the relevance of rehabilitation goals to achieve personally relevant goals for recovery, rehabilitation and social participation.

ACI published a booklet 'There's always hope'<sup>29</sup> to document the experience of people who were clients of BIRP services in stories, poems and art to benefit and inspire others.

### **5.3 The impact on families and the carer experience**

There is extensive literature describing the impact of brain injury not only on the person who sustained the injury, but also on their family. For almost four decades the significant emotional distress experienced by caregivers of persons with TBI<sup>30</sup> and the perspectives of siblings of people with TBI<sup>31,32</sup> has been documented.

When identifying the pertinent issues following paediatric TBI, Savage and colleagues<sup>24</sup> were able to determine that 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 TBI. Families also face many challenges themselves adjusting to the impact of the changes to the person with the TBI, as well as their own circumstances, e.g., giving up work to be a caregiver, 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:

- observers throughout all stages of the their loved one's care
- experts with a dual perspective of pre- and post-knowledge of abilities and difficulties
- communicators and liaisons with professional caregivers
- advocates for their family member.

In follow-up to the initial consumer experience publication, ACI published a second, 'Courage to care'<sup>33</sup>, to document the experience of family and carers of people who were clients of BIRP services in stories, poems and art to benefit and inspire others. These provide a description of the lived experience for carers of someone with a brain injury.

## 5.4 Geographical factors

Fifteen BIRPs aimed at providing an integrated continuum of specialised rehabilitation services for children, young people and adults under 65 years living in NSW with primarily severe or very severe TBI currently operate from metropolitan and rural centres. BIRP settings of care include adult inpatient, paediatric in-reach (subacute), transitional living, outpatient and community programs. As outlined in Section 3, the model and approach of BIRP teams varies between units providing similar programs and the configuration of staff is generally historical and influenced by organisational change and local decisions over time.

The 15 BIRPs are located in specific LHDs and operate in defined areas of NSW and ACT that are relevant to the type of program being provided. LHDs provide governance and financial management for the BIRPs located in their district. However, BIRP services are delivered across health district boundaries. The three adult inpatient services and the three paediatric in-reach services cover about a third of NSW each. All metropolitan services aim to retain contact and provide services when needed for clients and families who do not have access to the specialised brain injury rehabilitation services they need close to where they live.

In some areas of NSW, access to specialised rehabilitation services, including BIRP case management at the right time and close to where a person lives, can be problematic, particularly for people living in rural and remote locations. BIRP teams are not always resourced to provide the range of rehabilitation and case management services needed for all people in NSW of the type and intensity needed to improve, and regain, social roles. Distance, travel time and the need for staff to stay overnight are compounding factors in managing the geographical location of BIRP clients once discharged from centre-based services. The Far West LHD is particularly disadvantaged as people living in this area of NSW are often retrieved interstate for acute care and return home with little or no access to specialised brain injury rehabilitation, or even community rehabilitation. The nearest BIRP is several hours drive away or a short flight to Dubbo where there is a case management-only team with fly-in-and-out clinics.

The implementation, and consistency in using reliable new technology, needs to be available to all BIRP staff working with clients, families and service providers in rural and remote locations. Some technology is currently available, and in use, at different BIRP sites, but this is not always operational for all residents of NSW to access. Travel to centre-based services is the only current alternative to meet these needs.

In addition, evidence-based research regarding the effectiveness of different rehabilitation interventions being delivered using technology is still in its infancy. The application of technology and the efficacy of using technology for off-site therapy, clinics and case management services is an area of need for future research and development.

## 5.5 Workload factors

Case management services for BIRP clients including children, young people and adults of working age can be complex, demanding and stressful. It is important to understand caseload complexity to better manage the workload of BIRP case managers, so work output meets expectations to avoid staff stress and burnout.

Changes to funding and service expectations can impact on the demands and workload of BIRP case managers. The intermittent restructuring of health services, amendments to legislation, when and whether BIRP clients have access to a motor vehicle and workers compensation insurance schemes commonly influence the workload of case managers. A significant proportion of BIRP clients will meet scheme criteria under the *NSW Motor Accidents Compensation Act 1999* (NSW Government, 1999)<sup>34</sup> and *Motor Accidents (lifetime Care and Support Acts* (NSW Government, 2006 No 16;<sup>35</sup> 2014 No.77<sup>36</sup>), and this increases the demands and workload of BIRP clinicians. Under these pressures, sustainability of the workforce is a crucial factor in maintaining the structure and activities of BIRP case management across NSW.

### 5.5.1 Managing caseloads

Given the dynamic nature of the caseload and workforce issues, at some time most adult and paediatric BIRPs have trialled or reviewed ways to manage caseloads using complexity measures and classification systems.

In 2013, there were four main tools in current, or recent, use, which commonly reflected the perceived 'complexity' of each client receiving BIRP case management services. These four tools had been found useful in understanding caseloads, making decisions about assigning new clients for caseload management and recognising the skills and experience of case managers to work with complex clients and families. Interestingly, some BIRPs used the tools to manage client workloads for both case managers and therapy staff working in community teams. These four tools were providing a quantitative approach to classify caseload, providing information that could support change processes for increasing service efficiency and effectiveness. These tools were used to develop waiting lists to prioritise service provision according to resources available. The classifications also provide rationale to support requests for additional staffing when caseloads were very high. Despite the benefits there was little consistency in what and how the tools were used to support team processes across the network.

In 2014, a BIRD project was established to develop a state-wide caseload complexity measure. The first step was to audit the four main tools identified as being used by BIRP teams for the key elements and complete a literature review. Four client complexity measures were identified from the literature that was consistent with the project aims and able to be compared to the four tools being used by BIRP teams. These were:

- the Rehabilitation Complexity Scale<sup>37</sup>
- the INTERMED Complexity Grid<sup>38</sup>
- the Oxford Case Complexity Assessment Measure<sup>39</sup>
- Easley-Storfjell Patient Complexity.<sup>40</sup>

The elements from all of the eight tools and insights gained from the literature review were then developed into a complexity matrix. Consultation with clinicians and managers within the BIRP was important in further refining the complexity matrix and developing the nascent version of the Workload Capacity Tool to be trialled and evaluated within BIRP community teams for case managers and clinicians in May 2015.

### 5.5.2 Caseload versus workload

In the search for relevant literature, a relationship between caseload complexity and the number of clients who could be managed by one clinician was suggested across the international community in district nursing, community mental health services, and in a number of studies in different fields of allied health. This need for workload monitoring was found to be universal, and several themes were consistently raised in the literature in relation to their impact on the workers capacity to manage a caseload.

'When agencies refer to caseload management, the terms caseload and workload are often used interchangeably. However, there are distinct differences between the two terms. Specifically, caseloads are the number of clients using a program's services. Workload is the amount of time required to perform specific tasks related to contacting and providing services to clients. There is no universally accepted caseload/workload management system so flexibility exists in deciding how best to manage caseloads and corresponding workload. The primary control in case management is having sufficient data that allows managers to assess caseload and workload trends.'<sup>41</sup>

Monitoring the number of service users on a caseload is potentially misleading of actual workload and does not address other activities undertaken by practitioners is also supported by other authors including Butler (2006)<sup>42</sup>. Findings from several studies suggest that overall workload, more than caseload, is a contributor to stress in the case workers<sup>43</sup> and there are many other variables that contribute to the overall workload.<sup>44</sup>

This was summarised: 'Patient characteristics, case manager characteristics, characteristics of the service and support environment, geographical considerations and how new the patient is to the service have all been identified as being relevant to the workload associated with a case management caseload.'

It is therefore found to be a balance of:

- client factors (caseload complexity)
- worker characteristics
- processes and other work carried out by the clinician
- organisation, governance and management.

### 5.5.3 Implementing a workload tool for managing BIRP caseloads

The need to develop and use a community caseload management tool that encompasses the range of BIRP client and staff needs, as well as the various levels of program intensity and staff skill mix, was agreed by the BIRD executive in August 2013. Following this a project team was established to investigate the caseload of BIRP case managers. The aim was to increase the understanding of the elements and factors that impact on work capacity, and compile a suitable tool to monitor caseload capacity across paediatric and adult teams, and derive a fair and equitable guideline for expected work capacity for the long-term sustainability of the workforce. In collaboration with BIRP case managers, a project officer was recruited to develop, trial and finalise an agreed tool that is available for the state-wide network to provide a systematic approach to managing community caseload complexity and case manager workloads.

During the project the steering committee convened by BIRD agreed with the research that a workload approach was more consistent with the operation of BIRP community teams. A community workload management tool would be relevant to any BIRP clinician working in adult and paediatric community teams providing case management and/or other types of rehabilitation services. A BIRP community Workload Capacity Tool (WCT) was subsequently developed and piloted during 2015 at self-selected BIRP community teams. The tool is for use by adult and paediatric BIRP staff with case management only caseloads as well as those with mixed case management and/or clinical workloads. The final report will be available in February 2016.

In addition to caseload complexity, three additional factors were identified for inclusion in the complexity matrix for tool development. The four key characteristics of the WCT for managing workload in BIRP community teams include: caseload complexity, worker characteristics, work tasks and workplace factors. The components of these factors are explained in the following section.

#### 5.5.3.1 Client factors (caseload complexity)

Complexity can be defined as follows:

‘An issue is complex when it involves a variety of links to other aspects of the health and wellbeing of the individual. These are often hidden from view and can be linked to a wide range of social, cultural, environmental and economic factors. Patients have a critical and authoritative role in their own health and the interactive relationship with the service provider is a partnership built on trust, mutual respect, openness and personal responsibility.’<sup>45</sup>

The variables and domains identified in the mental health literature have a similar profile to the complexity of working with BIRP clients. The mental health literature identified several variables for caseload complexity and management in mental health case management that assist in understanding caseload complexity.<sup>46</sup> Some of the mental health case manager roles are directly relevant to the provision of BIRP case management. These include:

- extent of client needs (if response difficulty)
- contact frequency
- intervention type
- case manager competence
- caseload maturity (new versus established clients)
- geographical distribution.

In addition, several studies in the literature concluded that caseload complexity alone does not predict the most effective caseload size King (2004) and Simmons and Kuys (2011).<sup>47</sup> The variability in the BIRP teams, service types available and involvement with the injury management sector provide additional complexity.

#### *5.5.3.2 Worker (BIRP clinician) characteristics*

The skills and experience of each clinician is acknowledged in the matrix as this is a determinant of the number and complexity of clients any one worker can manage. Data on the various demographics and professional backgrounds of clinicians working in BIRP community teams was collected in the ACI Challenging Behaviour Project.<sup>48</sup> This information was used to understand community caseload management requirements. In addition, other measures described in the literature to measure various worker characteristics were evaluated for the purposes of the study of workload capacity. In the current project, the original protocol is repeated along with an adaption of the case manager Personal Efficacy Scale,<sup>49</sup> known in this study as PESCE.

#### *5.5.3.3 Work tasks (monitoring process and other work)*

Researchers of caseload complexity and clinician characteristics and others also determined that monitoring the number of service users on a caseload is potentially misleading with regard to actual workload and does not address the other activities undertaken by case management practitioners.<sup>50-53</sup> Findings from several studies agreed that there are many variables that contribute to the overall workload and non-clinical tasks need to be considered within workload assessment and management. Non-clinical tasks in a local brain injury setting have been categorised into: coordinating services, training, evaluation, and providing education.<sup>16</sup> There are also tools to capture all tasks undertaken by the worker. These were reviewed as part of the project but will not be routinely collected as it was considered to be an unreasonable burden to record such a high level of detail for the workload capacity study.

#### *5.5.3.4 Workplace (organisation, governance and management)*

These same researchers, and others identified that management and workplace policies regarding staff cover, absences and vacancies have an immediate impact on the distribution of work to other members of the team.<sup>54-56</sup> Some of the features discussed in this literature included absences, staff turnover, decision-making, organisational structure, resource allocation, task clarity, conflict resolution and mutual support/teamwork.

Questioning BIRP clinicians about 'what were the three things that impacted on your workload in the past month?' and determining from their managers the service supervision structure and actual working full-time equivalent positions (FTE; and vacancies and absences), provided the framework for identifying the workplace factors in the WCT impacting on case management services.

#### **5.5.4 Using the tool in clinical practice**

The tool provides the framework to assess each of the above four components in relation to an individual worker. Workload capacity can then be evaluated using minimal data collection for estimating the proportion of time spent in different roles / tasks. Adjustments are made based on FTE to acknowledge reduced capacity, particularly for part-time staff and those with both therapy and case management roles. The percentage of time spent in clinical tasks can then be separated from other factors influencing workload. Differences between individuals, within teams and across disciplines can then be used to evaluate the workload capacity and demands.

## 5.6 Funding

Overall, BIRPs receive a budget allocation from each LHD within which they operate, and injury insurance schemes provide the range of services required for the different settings of care. However, additional income is available to LHDs from insurance, particularly motor vehicle insurance, as this remains a primary cause of brain injury in people admitted to the BIRP.

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. Insurance is a fault-based injury compensation system.

Since 2006/2007 all people severely injured in motor vehicle accidents that meet scheme criteria, and regardless of fault, will have early access to the Lifetime Care and Support Scheme (LTCS). The scheme is funded by a levy on green slips to pay for treatment, rehabilitation and care for people who have been severely injured in motor accidents in NSW. This no-fault scheme provides interim participation following a motor vehicle accident for up to two years before needing to be assessed for lifetime participation. As at 30 June 2014, the Scheme includes 558 lifetime participants and 375 interim participants. People aged 20-24 years comprise the largest representation in the scheme (17%), followed by people aged 25-29 years old (12%). Traumatic brain injury remains the most common injury type (70% of adults, 90% of children). [www.lifetimecare.nsw.gov.au/about-us/annual-reports](http://www.lifetimecare.nsw.gov.au/about-us/annual-reports)

Fee for service payments are provided for BIRP services as outlined in the NSW Health Policy Directive (PD2014\_019) and updated annually. 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; and 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 two-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.

# Section 6

## Evaluation of BIRP case management

Evaluating case management outcomes is difficult. The lack of consensus or discussion on approaches to evaluating the outcomes from case management reflects the embryonic state of research regarding brain injury case management. This required literature specific to other diagnostic groups, including dementia and psychiatric conditions, to be reviewed to identify the parameters for outcome measurement.

A summary of this research is provided in Appendix 6.

Three approaches to evaluation were identified – clinical indicators, outcome measures and process indicators.

- **Clinical indicators** are a measure of the clinical management and/or outcome of care. In the case management context this can apply to ‘real-life’ parameters, including service use data, qualitative data on behaviour and other psychosocial functioning variables.
- **Objective measures of outcome** can focus on different aspects of client functioning and change. Due to the complex nature and aims of case management interventions designing and choosing appropriate measures to evaluate case management outcomes is difficult. A broad range of parameters is usually considered in measures aiming to assess case management outcomes. A heterogeneous range of measures used to evaluate outcomes are documented in the literature and no gold standard tool was identified for this purpose.
- **Process indicators** include the intensity of case management services provided to individual clients, such as frequency of visits and time spent with clients, as a proxy to quality of service. They are usually easier to measure but it is difficult to ascribe process measure outcomes to client improvement.

Sullivan and Fisher (1994)<sup>57</sup> observed that ‘case management as implemented and described in professional literature, suggests such widely diverse activities and desired outcomes that the term now has no innate meaning’. Selecting the framework for measuring case management outcomes may need to consider these three elements, and yet remain feasible and sustainable.

The measurement of BIRP case management outcomes can be framed in the context of a clearly defined role and model of BIRP case management. National and international literature and current practice in BIRP services already provide some options for an evaluation framework for case management using the World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF), standardised global measures of client outcomes and process measures.

### 6.1 Using the International Classification of Functioning, Disability and Health to identify the data to collect

The ICF was developed to address the impact of health conditions from a bio-psychosocial perspective. This major revision of the original model moved from a linear concept of the relationship between disease, health and disability to a more comprehensive framework involving biological, psychological, social and environmental aspects that acknowledges the dynamic nature of the experience of health and the influence of the context in which a person lives.<sup>58,59</sup> The ICF has been used to describe the impact of brain injury at the level of the person and service systems. All of the domains can be used to describe the impact of brain injury, including the person’s impairments, body functions and structures, and their level of disability in relation to activity limitations, participation restrictions and the supportive and confounding influence of their social, physical and cultural environment in which they live.

The 'Comprehensive ICF Core Set for TBI', published by Laxe and colleagues, lists 139 of the most pertinent ICF categories to describe the aspects of functioning relevant to persons with TBI.<sup>60</sup> The aim was to provide some standardisation to inform development and use of outcome measures with people with brain injury, although the routine use of 139 items is unlikely to be feasible in the context of clinical practice.

To increase clinical utility, a Brief ICF Core Set for TBI with 23 items (See Table 4) was developed to serve as a minimum international standard for the reporting of functioning in persons with TBI along the continuum of care (ranging from the acute hospital through to community reintegration) and across sectors (health, labour and social affairs).

Table 4: List of 23 items included in the TBI Brief Core Sets

Body Functions (8)	Body Structures (1)	Activities & Participation (8)	Environmental Factors (6)
b164 Higher-level cognitive functions	s110 Structure of brain	d230 Carrying out daily routine	e310 Immediate family
b152 Emotional functions		d350 Conversation	e580 Health services, systems and policies
b130 Energy and drive functions		d450 Walking	e115 Products and technology for personal use in daily living
b760 Control of voluntary movement functions		d720 Complex interpersonal interactions	
b144 Memory functions		d845 Acquiring, keeping and terminating a job	e320 Friends
b280 Sensation of pain		d5 Self care	e570 Social security services, systems and policies
b140 Attention functions		d920 Recreation and leisure	e120 Products and technology
b110 Consciousness functions		d760 Family relationships	

The ICF Core Sets for TBI are not intended to serve as health status measure, but are intended as an international standard of what to include when measuring outcomes after brain injury. It could also serve as a practical checklist for aspects to include in assessment and intervention for working with people with TBI in the context of specialised brain injury rehabilitation programs in NSW.

## 6.2 Objective measures of BIRP community client outcomes

### 6.2.1 Adult clients

The Mayo-Portland Adaptability Index (MPAI)-4 has been mapped to the ICF and from the 30 items, 88 meaningful concepts were matched to ICF domains.<sup>61</sup> The MPAI-4 has items across the ICF domains for body function, activity, participation and environment. Domains of interest for measuring clinical indicators, case management outcome and processes for adult BIRP clients grouped according to the WHO ICF have been provided in Appendix 4.

The MPAI-4 is a global measure of outcome after brain injury and provides comprehensive information about a person's functioning. The MPAI-4 can be used to identify clinically relevant individual change in a proportion of the adult BIRP population with severe brain injury using key form charts. In addition, analysis of group change within different clinical pathways for community clients is possible.

The MPAI-4 was introduced to BIRP community teams in January 2012 following the conclusion of the ACI Community Outcomes Project.<sup>62</sup> The adult BIRP community teams use the MPAI-4 to collect outcome data at admission and discharge and, where relevant, at two years post-admission and then annually until discharge. However, there are methodological problems in using a global outcome measure to understand the results achieved by case management alone. Additional measures may be needed to capture more specific case management outcomes.

Adult BIRP clinicians use the Care and Needs Scale (CANS)<sup>63</sup> as standardised measures, but only for those clients who are also participants of the LTCS scheme. This measure is not useful for determining outcomes for BIRP case management interventions.

### 6.2.2 Paediatric clients

There are no subacute national or state benchmarks, or even an agreed clinical measure of outcome for children with ABI. Paediatric Australian National Subacute and Non-Acute Patient (AN-SNAP) classifications are currently under development for planned implementation in July 2015.

Paediatric BIRP clinicians use the Wee-Functional Independence Measure (WeeFIM) instrument<sup>64</sup> and Paediatric CANS (PCANS-2)<sup>65</sup> as standardised measures, but only for those clients who are also LTCS participants. There is no agreed measure of outcome routinely used for all BIRP paediatric clients to measure individual outcomes or outcomes from BIRP case management interventions. Several standardised measures were trialled, but were unsuitable to adopt within the BIRP paediatric service context.

The BIRD Paediatric Reference Group has identified the need for further research to propose and agree to an appropriate approach for measuring paediatric and young adult outcomes from specialised brain injury rehabilitation that may assist in determining global outcomes or more specific outcomes from paediatric BIRP case management.

### 6.2.3 Client-centred rehabilitation goals

The evaluation of client-centred goals provides another opportunity to measure case management outcomes as clients collaborate to identify goals they wish to achieve. This may be broader than discrete changes to function and more likely to capture some of the more diverse aims of case management interventions. Currently some BIRP teams utilise electronic systems to record client goals developed by the team at case conferences.

A BIRD working group involving BIRP clinicians aimed to improve the quality, process and formulation of client-centred rehabilitation goals with the longer-term aim of utilising goal achievement as a client outcome measure. While measuring goal attainment was reported as an approach used to measure client outcomes in BIRP, the quality of goals set often focused on process changes.

BIRD facilitates discussion and implementation of processes within BIRP teams to ensure quality goal practices are embedded in client planning and reporting.

Working collaboratively with adult and paediatric BIRP clinicians to improve standards in client-centred goal-writing skills is the first step for measuring outcomes from client-centred rehabilitation goals. This has the potential to support the trend for patient-reported outcome measures. Some individual BIRP teams are using goal attainment to understand and support local practices.

## 6.3 Process outcomes

Clinicians need to record occasions of service (OOS) data as a unit of time. OOS data is collated, analysed and reported at both the LHD and NSW Ministry of Health levels. The Ministry of Health provides the policy guidelines for the 'Non-Admitted Patient Activity Reporting Requirements' that are implemented locally. For more information visit [http://www.health.nsw.gov.au/policies/pd/2013/pdf/PD2013\\_010.pdf](http://www.health.nsw.gov.au/policies/pd/2013/pdf/PD2013_010.pdf)

Generally, OOS data is entered according to allied health discipline and not as BIRP case managers. This restricts interpretation of the data to support outcomes about the process of BIRP case management by measuring the direct client activity of the BIRP case manager.

In addition, the ACI BIRD supports the development and use of a clinical data set for collecting and reporting BIRP activity, project initiatives and research. The BIRD annual report provides de-identified demographic, injury, setting of care and some client outcome data. Data collected is made available for local planning and service reviews.

The BIRP case manager may be involved in the collection of data at various times during the case management episode.

# Section 7

## Workforce

The role of the case manager working with people with TBI/ABI in the BIRP and the BIRP service structure is unique both in Australia and internationally.<sup>66</sup>

Across the services, BIRP case managers variously work full- or part-time and are primarily recruited from nursing and allied health backgrounds. A range of titles are in use across the services for the role of case manager. Titles include 'Case Manager'; 'Community Rehabilitation Worker'; 'Rehabilitation Coordinator' etc. Despite the different titles used locally by BIRP services, all staff in these roles work in the same way when providing case management interventions.

The clinical role of case manager in the brain injury public rehabilitation setting is not a recognised health profession, so there is no separate award classification in NSW Health. Health professionals working in this role are usually paid according to qualifications, so within the case management position descriptions the clinical aspects of the role need to be defined. In circumstances where case management is 100% of the duties, maintaining professional registration requirements can be problematic when these are linked to profession-specific standards.

### 7.1 BIRP case manager profile

In the absence of a professional health award for case managers, the focus in this section is on defining what BIRP case managers do and what makes a good case manager. The purpose of developing an agreed case manager profile is to provide a professional framework that includes critical clinical aspects of the role that reflect the specialised rehabilitation approach when working with BIRP clients and their families.

The agreed case manager profile can be utilised by BIRP services as a template for developing position descriptions when recruiting and employing the right person for case management duties, to identify clinical areas for skill development, and for mentoring and professional development opportunities. In addition, case manager competencies and learning resources can be developed from the case manager profile for any additional requirements to work in BIRP case management.

#### 7.1.1 Background

In 2006, the rehabilitation case manager's network of public and private providers developed the following unpublished profile:

- clinical reasoning in brain injury rehabilitation
- the ability to design, implement and modify pathways for goal achievement across all domains of the client's life
- knowledge and understanding of external agencies and systems relevant to education, employment, health, independent living skills, accommodation, community participation, compensation and legal representation
- flexible, responsive and adaptable approaches to client needs
- creativity and innovation
- maintaining a vision of where the individual would have been without the injury.

The BIRD steering committee incorporated and expanded this profile when identifying what makes good case managers working in the BIRP teams. Information from a review of BIRP adult and paediatric case manager position descriptions and recruitment information was collated and reviewed by the steering committee to develop the profile that reflects the skills, knowledge, understanding, attitude and qualifications of clinicians working in BIRP case management positions.

### **7.1.2 Profile**

The BIRP case manager profile includes:

- clinical skills
- knowledge
- experience
- attitude
- qualifications.

The specific detail for each of these areas is provided in Appendix 5.

The BIRP case manager profile supports the recruitment of knowledgeable and skilled staff able to function independently as a core team member involved with the client, family and rehabilitation team for planning, implementation and achieving identified goals. The profile, provided as a template, can assist in reviewing and developing position descriptions for recruitment of a BIRP case manager, as well as identifying the gaps in the case management team when recruiting a new BIRP case manager.

The profile provides valuable information for professional development in identifying knowledge and resources within the team, as well as what education and training needs to be accessed externally. There is limited education and training available for improving the knowledge and skills of clinicians working in BIRP case management roles. For this reason, the necessary skills required of the case manager may include elements such as motivational interviewing, solution-focused therapy and family-sensitive practice that can be appropriately adapted to working specifically with the client and family following TBI. Criteria for recruitment can include LTCSA Approved case manager status. This can be gained during employment.

### **7.1.3 National accreditation**

The first national standards of case management practice were introduced and later revised by the CMSA. These national practice standards and a code of ethics are available to support the case management framework for practice in Australia. A self-assessment framework supports the vocational pathways process to achieve case manager accreditation. Certification encourages accountability, ensures consumer protection is a practitioner's highest concern and underscores a practitioner's ability to work effectively in today's multidisciplinary team environment.

The value of national certification and training for BIRP clinicians working in case management roles is limited, particularly in the absence of a NSW Health professional award for case managers. This means that all current BIRP case managers have a professional background that incorporate the elements of values, principles, and ethical and professional conduct. In addition all NSW Health employees sign a code of conduct and need to abide by the NSW Health values and principles as well as various policies (e.g. harassment in the workplace, working with children etc.).

Nationally accredited case managers who do not meet NSW Health specific criteria for professional awards (e.g. allied health and nurses awards) may have difficulty receiving the right pay for the specialised case management training and skills they bring to the role.

### **7.1.4 Injury management sector**

A significant number of clients admitted to the BIRP and assigned case managers have entitlements with injury-related insurance schemes. BIRP case managers require an understanding of the schemes and their operation to assist clients and families access entitlements.

In 2011, a case manager approval process was introduced by LTCSA for scheme participants. The skills involved were subsequently included in the BIRP case manager profile. LTCSA developed training focused on improving the ability of clinicians to provide case management services to scheme participants. The BIRP services have a mix of approved and new LTCSA case managers.

The introduction of the approved case manager status for scheme participants has changed the expectation in BIRP teams to achieve this accreditation. It has also expanded the workplace supervision and mentoring responsibilities of experienced case managers and team leaders to support less experienced and new BIRP case managers.

## 7.2 BIRP case manager education and training

Education and training for case management is not currently included in the health professional curriculum or as a separate health profession. The model of case management is often linked to the service or program within which a case manager works rather than being driven by a set of professional principles. Recruitment of health clinicians to BIRP case management positions provides a professional standard that forms the basis for development of specific skills in case management and working with people with TBI, their families and a variety of other health and non-health providers.

Clearly identifying education pathways can build workforce capacity by encouraging interested people to move into case management. This can be achieved by enabling people to choose case management training courses and access learning resources that are relevant to the type of case management being provided. This knowledge can then be applied across different service delivery models and disability types.

Formal training to apply case management to specialty clinical areas for people with ABI is generally unavailable. The education pathways to build knowledge and skills within different service sectors are primarily a service responsibility. The quality of training a case manager receives is therefore variable, often relying upon peers within the BIRP or agency to which the person has been recruited.

### 7.2.1 Orientation for BIRP case managers

There is no state-wide orientation program for clinicians recruited as BIRP case managers. Orientation is supported locally with access to resources and experienced case managers to assist and support on the job learning and identify skills for development. A buddy system supports understanding of the service approach and expectations for new case managers.

Orientation can include visits to other BIRPs to meet with case managers and build understanding of the role and function of the position as well as the being introduced to the case management network of services in specialised brain injury rehabilitation.

As BIRPs operate within NSW Health, staff has access to the Health Education and Training Institute (HETI) learning and development resources. HETI has established performance development and mentoring processes for meeting identified needs.

BIRP case managers also have access to self-learning and presenter modules for case management and other introductory modules and toolkits that may be useful when working with people with TBI. These can be accessed via [www.tbistafftraining.info](http://www.tbistafftraining.info). The website has had a focus on general disability and rehabilitation staff and is expanding to include learning resources for clinicians working in specialised brain injury rehabilitation services.

### 7.2.2 Specific training to support everyday practices

Specific workshops and training that are useful and relevant for BIRP case managers to improve clinical skills are provided from time-to-time by BIRD and BIRP teams, as well as key stakeholders.

#### 7.2.2.1 Client-centred goal training

Although goal-setting is an essential part of rehabilitation it is typically neglected in undergraduate training, and variations in practice may be taught in different professions.

The BIRD and LTCSA are working collaboratively to reduce variation in goal-writing in the injury management sector as consistent high-quality goal-setting will reduce the likelihood that inadequacies in goal-setting will compromise client care, such as limiting client motivation, impeding treatment planning, funding approvals and compromising communication with all stakeholders.

The BIRD developed a goal-training program, including a training workbook, as a learning resource to improve BIRP clinician skills in client-centred goal planning and support insurers to consistently utilise client goals for injury management plan.<sup>67</sup> This provides the potential to use goal attainment to supplement the results of standardised measurement of individual and service outcomes.

BIRP clinicians have attended goal training during the funded project and are now able to access funder-provided training sessions from time to time. This provides the core training for BIRP staff, particularly when new to the sector. BIRD staff continues to work with BIRP teams to improve the consistency and quality of goal-writing skills, to better reflect individual progress and rehabilitation team involvement.

### 7.2.2.2 Standardised outcome measures

BIRP case managers are able to access external training for standardised outcome tools relevant to their roles e.g., FIM and WeeFIM training, CANS and PCANS-2.

The BIRD provides BIRP clinicians with education and training on request about the standardised outcome measures used in the transitional and adult community settings of care. Training manuals and guides are available at each BIRP location as a local reference.

### 7.2.2.3 Motivational interviewing

Motivational interviewing techniques are frequently used in other health sectors. Courses are externally available and sometimes included in local health and community training calendars. However, this training does not specifically apply to working with people with cognitive and/or behaviour change following TBI. The BIRD is developing a motivational interviewing training module for case managers and clinicians working with people with traumatic brain injury.

### 7.2.2.4 Team-specific training

BIRP services are able to identify and organise relevant training, presentations and workshops for their team in priority areas of TBI rehabilitation. In the workplace, a BIRP case manager has access to a range of TBI-specific learning resources and expert clinicians to assist in building knowledge and skills when engaging with clients/families, and in different aspects of their role.

### 7.2.3 Externally provided training

Education and training that is useful and relevant for a BIRP case manager will usually be accessed as a component of professional development. Other courses to meet specific individual training needs can be accessed via the internet.

Charles Sturt University provides the opportunity for a single subject study by distance education through the Associate Student Program (course WEL221) offered by the Continuing and Professional Education Centre for Acquired Brain Injury.

## 7.3 Conferences

### 7.3.1 NSW BIRP Forum

This is organised with support from the ACI every second year with, and hosted in rotation by, the Sydney metropolitan BIRP services. The aim of the forum is to provide clinicians and interested others with up-to-date concepts and evidence-based research upon which to base their work. The forum provides a platform for state, national and international speakers to present research, clinical practices and new initiatives. The forum incorporates adult, paediatric and rural streams. BIRP clinicians are encouraged to participate, submit abstracts and present, with some support available to attend, if needed.

### 7.3.2 Australasian Society for the Study of Brain Impairment (ASSBI)

ASSBI is a multidisciplinary society dedicated to improving the quality of life of people with brain impairment and their families. Membership of the ASSBI is available to allied health and medical professionals, academics and researchers, and individuals working or involved in brain impairment. ASSBI provides:

- a forum for Australasian professionals working in brain impairment
- publication of the journal *Brain Impairment*
- sponsorship of PsychBITE database consisting of published treatment studies that address psychologically-based disorders arising from brain impairment
- in conjunction with Moving Ahead, a Centre of Research Excellence in Brain Recovery for clinician education and resources.

### 7.3.3 Others

International conferences for brain injury and discipline-specific conferences can be accessed via the internet. Examples include the:

- World Congress on Brain Injury
- International Brain Injury Association Conference
- Conference of Neuropsychological Rehabilitation Special Interest Group of the World Federation for Rehabilitation.

# Section 8

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- 62 Badge H. (2012). 2012 – 2017 Manual: *Outcome Measurement For Adult Services: Community based and TLP Settings of care. Volume 1: Background & Reference Material*, Version 1.0. Sydney: NSW Agency for Clinical Innovation.
- 63 Tate RL. (2011). Manual for the Care and Needs Scale (CANS). Unpublished manuscript, Rehabilitation Studies Unit, University of Sydney. Revised version 1.
- 64 Uniform Data System for Medical Rehabilitation 2006. The WeeFIM II Clinical Guide, Version 6.0. Buffalo: UDSMR.
- 65 Tate RL, Soo CA, Wakim DM. (2013). Manual for the Paediatric Care and Needs Scale Version 2 (PCANS-2). Rehabilitation Studies Unit, University of Sydney.
- 66 Simpson GK and working group. (2010). *Investigation into the model of case management in the NSW Brain Injury Rehabilitation Program*. BIRD Internal Report. Sydney: NSW Agency for Clinical Innovation.
- 67 Badge H, Weekes M, Jones B, Strettles B. (2013). *Goal Training Participant Workbook*. Sydney: Agency for Clinical Innovation. Available at <http://www.tbistafftraining.info/Presenters/Goals/GoalTrainingWorkshop.htm>
- 68 Ylvisaker M, Feeney T. (1998). *Collaborative brain injury intervention: Positive everyday routines*. San Diego: Singular Publishing Group.
- 69 Prigatano GP. (1999). *Principles of Neuropsychological Rehabilitation*. 1st edition. Oxford University Press, Inc., New York.
- 70 Willer B, Corrigan J. (1994). Whatever it Takes: A model for community-based services. *Brain Injury*, 8:647–659.

# Section 9

## Appendices

### 9.1 Appendix 1: BIRP case management survey

#### 9.1.1 Background:

The BIRP case management survey was a purpose-designed measure devised to collect data on a number of organisational and service delivery aspects related to the provision of BIRP case management within participating units. It was developed as a major tool to gather data to address a number of the key issues to be investigated for developing the model of BIRP case management.

Included in survey design were components from the literature that appeared to be consistent with BIRP case management service provision. A survey completed by 40 paediatric ABI case managers, representing 24 different organisations was of particular value.<sup>16</sup> Eight service components were identified and ranked in order of importance.

The eight components included:

1. coordination of services
2. liaison
3. education
4. referral to other services
5. goal-setting
6. counselling
7. preparing rehabilitation plans
8. group work.

The design of the BIRP community team case management description survey was completed and the survey was then administered to managers and clinicians in BIRP adult and paediatric services to identify support and develop the new model of BIRP case management. The survey is provided on the next page.

### 9.1.2 Survey of BIRP community team case management descriptions

Thank you for taking the time to help this QA project examining approaches to case management among BIRP community teams.

**The survey comes in two parts.**

<b>Service managers:</b>	Please complete Part I Qs 1–5. Only complete Part II of the survey if you also have a clinical case management role.
<b>Community staff:</b>	Please complete Part II Qs.

Your responses will remain confidential and any data reported in aggregate so that individuals cannot be identified. The results constitute the first step to a larger project examining the outcomes from case management.

If you have any questions, please do not hesitate to contact \_\_\_\_\_ on ph. 9828 6353 or by e-mail\_\_\_\_\_.

## Community team case management description survey

### Part I. Service questions answered by manager

#### 1. Do you separate your case management and therapy roles? Is the team approach (please tick the best option)

- Multidisciplinary      Some staff specialise in case management, others solely in therapy roles
- Interdisciplinary      All staff provides a mix of case management plus their own therapy/professional roles
- Transdisciplinary      All staff provides a mix of case management plus a range of therapy roles
- Other      \_\_\_\_\_

#### 2. Describe your model in the context of the community rehabilitation service? (please tick the best option)

- Case management      Assessment, monitoring, referral plus direct service role
- Case monitoring      Assessment, monitoring, referral only
- Advocacy      Assessment, advocate for services, monitor outcomes
- Brokerage      Assessment, sub-contract services, monitor outcomes
- Case administration      Reviewing plans submitted by others, authorising expenditure, monitoring costs

Any Others \_\_\_\_\_  
\_\_\_\_\_

3. What title does staff have? \_\_\_\_\_  
(eg. rehabilitation coordinator, case worker, case manager)  
\_\_\_\_\_

**4. What are the entry and exit criteria for your community team?**

Entry \_\_\_\_\_  
\_\_\_\_\_  
Exit \_\_\_\_\_  
\_\_\_\_\_

**5. How many FTEs do you have in case management roles in your team?**

\_\_\_\_\_

**Part II. Service questions answered by staff**

Case management description project (please circle your response) ID \_\_\_\_\_

1. Are you? Male Female

2. How many years have you worked in the brain injury field?

0-1 2 3 4 5 6 7 8 9 10 If >10 \_\_\_\_\_ yrs

3. (a) What is the title of your position? \_\_\_\_\_

(b) What is your professional background?

Nursing Allied health psychosocial (Social work, social welfare, psychology)  
Allied health rehab (OT, physio, speech, rehab counsellor)  
Case Management Other \_\_\_\_\_  
\_\_\_\_\_

4. What proportion of your time involves case management vs therapy? (please circle one number in each column)

Case management	Therapy
0%	0%
10	10
20	20
30	30
40	40
50	50
60	60
70	70
80	80
90	90
100%	100%

Please make sure the two figures add up to 100%.  
For example (CM 100% – therapy 0%)  
or (CM 50% – therapy 50%)



**6. Below there is a list of case management roles. Please rate these roles in the following way:**

**Ranking roles by time (Rank 1–10)**

In the column RANK, rank the roles in order from 1 (indicating the role that takes up most of your time) to 10 (the role that takes up least of your time). If there are roles that you do not do, leave them blank. Do not rank them.

**Estimating the amount of time (time estimate)**

In the column **Time estimate**, estimate in percentages the amount of time you spend on each role. For example, assessment 20%, goal setting 20%, individual support 30%, referral/liaison 25%, advocacy 5%.

Make sure your estimates add up to the total of 100%.

Survey: list of case management roles			
Roles	Descriptors (examples only)	Rank 1 – 10	Time estimate
<b>Assessment</b>	Face-to-face with client (assess expressed needs), family (assess needs), assess interaction between client and broader social environment		
<b>Individual support</b>	Provision of emotional support, conflict resolution, adjustment (incl. info re disability) / loss and grief issues, compliance / motivation, challenging behaviours, cognitive management, practical support		
<b>Referral &amp; liaison</b>	Identifying resources, finding out about other services, writing reports (contact to discuss), problem-solving, clarifying roles, communicating information, dealing with bureaucracies as below <sup>1</sup>		
<b>Coordination</b>	Conferences with clients, families, team staff, staff from other agencies		
<b>Monitoring / review</b>	Mental health state, learning about people and their preferences, early identification of problems/trouble shooting, help keep on track with plans, review goals, observation, check on progress, encourage		
<b>Family social / support</b>	Facilitate individual decision-making, support families and friends. Provide information re disability, management/support strategies		
<b>Goal-setting / support planning</b>	Short-term goals, long-term goals		
<b>Education</b>	Educating others re service, staff from other agencies about BI, educating individual/family		
<b>Advocacy</b>	Identify needs and service gaps, negotiating with large organisations, aiming to have gap/need filled		
<b>Community / service development</b>	Use of statistics, identifying gaps, preparing submissions, create options with generic services		

**Please return the survey to your service manager.**

<sup>1</sup> Welfare (Centrelink, Department of Housing, legal (insurance, solicitors, Legal Aid, police, probation, court, corrective services), immigration education (school, TAFE, university), carer agencies, Office of Protective Commissioner, Office of the Public Guardian

## 9.2 Appendix 2: Service context

### 9.2.1 Background to BIRP case management model development

One of the distinct elements of BIRP services since establishment in the 1990s has been the combination of brain injury rehabilitation case management and outreach/community-based therapy. This innovative approach may have anticipated the contextually-based rehabilitation described by Ylvisaker and Feeney (1998).<sup>68</sup> They argue that brain injury rehabilitation is most effective when it takes place in the community environments in which people live and function.

The BIRP approach to community-based rehabilitation shares this focus. Case management within BIRP developed from the ground up, in tandem with the establishment of BIRP community rehabilitation teams. As each team developed, different service delivery platforms in terms of service and team structures evolved, shaping the way that case management was incorporated into the BIRP service delivery model.

In 2007, clinicians in the BIRP formed the original working group interested in examining the role of case management within the adult BIRP services and internationally. There had been no previous attempts to review, describe and evaluate the contribution of case management to the community reintegration of BIRP clients. The initial working party represented five adult BIRP services: North Coast Brain Injury Rehabilitation Service, New England Brain Injury Rehabilitation Service, Mid Western Brain Injury Rehabilitation Program, Dubbo Brain Injury Rehabilitation Program and Liverpool Brain Injury Rehabilitation Program. Westmead Brain Injury Rehabilitation Service joined in late 2008 and a year later the working group also included Royal Rehab BIRS, Ryde and South West Brain Injury Rehabilitation Service, the latter bringing paediatric case management perspectives to the working group.

The working party completed a review of the existing ABI case management publications and concluded that the literature was at an embryonic stage, fragmented and extremely limited in its ability to inform work on delineating the BIRP model of case management and approaches to measuring case management outcomes.

A project was then initiated to take a heuristic approach to developing a service model out of the existing experience and operation of case managers in the BIRP teams. A dynamic process followed with new tasks being identified as the project progressed.

An internal report on the investigation into the model of case management in the BIRP was completed and the results presented to the BIRD meeting of BIRP directors and managers in August 2010 to consider the recommendations. Finalising the BIRP model of case management was accepted as a priority issue by the BIRD executive.

To achieve a whole-of-network approach a steering committee involving all BIRPs was convened to implement the recommendations of the internal report. At this time, the remaining six BIRP services (three adult and three paediatric) were engaged to ensure that the model of case management was applicable to, and agreed on by, all adult and paediatric BIRP services. The aim of the steering committee was to complete the BIRP case management model of care involving clinicians from the adult and paediatric BIRP teams.

### 9.2.2 The NSW Brain Injury Rehabilitation Program

The BIRP comprises 15 specialist brain injury rehabilitation services for the population of NSW located in metropolitan and regional centres. Children, young people and adults of working age with severe TBI are the primary admission group. Compensable and non-compensable clients can be admitted.

The BIRPs share eight underlying principles:

- early intervention
- continuum of care
- case management
- interdisciplinary teamwork
- client and family involvement
- goal-directed rehabilitation
- least restrictive environment
- innovation and best practice.

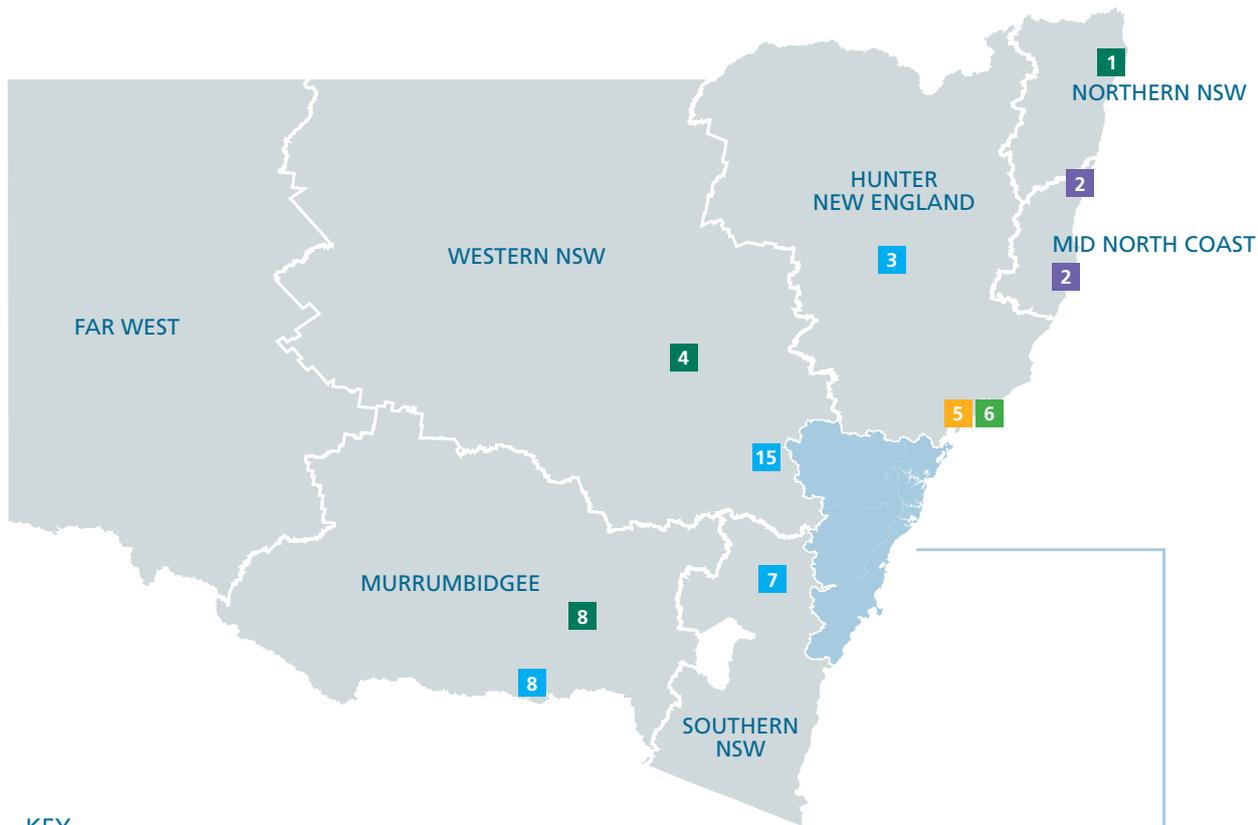
The great majority of people who access BIRP services have TBI with a significant subset (approximately 20% of all BIRP admissions annually) having other forms of ABI. The majority of people admitted with TBI have severe to extremely severe injuries, although people with complex mild or moderate TBI are admitted.

There are five settings of care comprising BIRP services. They are described as adult inpatient, paediatric inpatient, transitional living, adult community and paediatric community. 'Adult inpatient' refers to dedicated inpatient beds, while 'paediatric inpatient' is a dedicated team providing acute in-reach and subacute in-reach services in the three paediatric trauma hospitals. Five of eight rural adult teams have co-located paediatric coordinators to support paediatric clients and families returning home. SWBIRS has a multidisciplinary Kids Team to provide support and specialised rehabilitation for paediatric clients returning home. Two rural BIRPs do not include paediatric brain injury rehabilitation services. There are no specialist brain injury transition workers in the BIRP to facilitate the change from paediatric to adult services.

In December 2012, one BIRP was divided according to LHD boundaries providing a total of 15 BIRPs for NSW residents. This now includes 12 adult BIRPs (four metropolitan and eight rural) and three metropolitan paediatric BIRPs. Five rural BIRPs have co-located community paediatric services (one paediatric team and four rural paediatric case manager-only teams).

The location and types of BIRP services available for the people of NSW are provided in the map over the page. The map includes the LHD boundaries.

# Map: BIRPs by Location



## 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



### 9.2.3 The rehabilitation approach in the BIRP

Brain injury rehabilitation in NSW reflects a number of international models within different BIRP services. SWBIRS (Albury) originally styled their residential service on the Prigatano neuropsychological model.<sup>70</sup> NCBIRS (now separated into Northern BIRS and MNCBIRS) originally adopted the 'Whatever it takes' community participation model.<sup>71</sup> LBIRU developed a social rehabilitation model which reflected a person-in-environment approach to community rehabilitation.

Despite these differences in emphasis, as a generalisation the holistic bio-psychosocial medical approach is the predominant model in Australia and within the BIRP. Within this context, community rehabilitation is the framework for participation-focused BIRP case management. There has been a strengthening of neuropsychological and neurobehavioural elements within the teams by introducing cognitive therapists/ rehabilitation psychologists and clinical psychologists, as well as the training of BIRP rehabilitation staff in skills that enable them to deliver services tailored to address the cognitive and behavioural challenges of clients with TBI/ABI.

### 9.2.4 Agency for Clinical Innovation

The ACI works with clinicians, consumers and managers to design and promote better healthcare for NSW. It does this by:

- **Service redesign and evaluation:** Applying redesign methodology to assist healthcare providers and consumers to review and improve the quality, effectiveness and efficiency of services.
- **Specialist advice on healthcare innovation:** Advising on the development, evaluation and adoption of healthcare innovations from optimal use through to disinvestment.
- **Initiatives including guidelines and models of care:** Developing a range of evidence-based healthcare improvement initiatives to benefit the NSW health system.
- **Implementation support:** Working with ACI Networks, consumers and healthcare providers to assist delivery of healthcare innovations into practice across metropolitan and rural NSW.
- **Knowledge sharing:** Partnering with healthcare providers to support collaboration, learning capability and knowledge sharing on healthcare innovation and improvement.
- **Continuous capability building:** Working with healthcare providers to build capability in redesign, project management and change management through the Centre for Healthcare Redesign.

ACI Clinical Networks, Taskforces and Institutes provide a unique forum for people to collaborate across clinical specialties and regional and service boundaries to develop successful healthcare innovations.

The BIRD has a small dedicated team with a focus on engaging the BIRP network of clinicians, consumers and stakeholders in improving outcomes for admitted clients. The BIRD is a partner with the LBIRU research team in the Brain Injury Rehabilitation Research Group at the Ingham Institute of Applied Medical Research, Liverpool. The partnership promotes a collaborative approach to health service planning and clinical research.

A priority for the ACI is identifying unwarranted variation in clinical practice and working in partnership with healthcare providers to develop mechanisms to improve clinical practice and patient care. Visit [www.aci.health.nsw.gov.au](http://www.aci.health.nsw.gov.au) for more information.

## 9.3 Appendix 3: Summary of the literature

### 9.3.1 Case management references in other health conditions

Table 5: References for case management in other health conditions

Number	Authors	Year	Source
1	UK700 case management trial	2000	<i>British Journal of Psychiatry</i>
2	Walsh et al.	2001	<i>BMJ</i>
3	Curtis et al.	1998	<i>Psychiatric services</i>
4	Ziguras & Stuart	2000	<i>Psychiatric services</i>
5	Clark et al.	1998	<i>Health Services Research</i>
6	Wolff et al.*	1997	<i>American Journal of Psychiatry</i> (*see also Morse et al, 1997, <i>Psychiatric Services</i> for another review of this study)
7	Evans & Hendricks	2001	<i>Disability and Rehabilitation</i>
8	Ercole et al.	1997	<i>Psychiatric Services</i>
9	Bernabei et al.	1998	<i>BMJ</i>
10	Lim et al.	2003	<i>MJA</i>
11	Burns et al.**	1999	<i>The Lancet</i> (** see also Huxley et al. 2001,
12	Marshall et al.	1995	<i>The Lancet</i>
13	Mueser et al.	1998	<i>Schizophrenia Bulletin</i>
14	Björkman et al.	2002	<i>Social Psychiatry and Psychiatric Epidemiology</i>
15	Newcomer	1999	<i>Health Services Research</i>
16	Gagnon et al.	1999	<i>American Geriatrics Society</i>
17	Sulkava et al.	2001	<i>American Geriatrics Society</i>
18	Gerdner et al.	2002	<i>Nursing Research</i>
19	Summers	1996?	<i>Centre for Health Program Evaluation</i>
20	Tyrer et al.	2003	<i>The British Journal of Psychiatry</i>
21	Fitzsimmons	2003	<i>Brain Injury</i>

### 9.3.2 Brain injury case management literature review summary table

Table 6: Summary of the literature

Year	Author	Definitions of case management	Rehab continuum	Design	Sample	Measures	Outcome	Key point
1988 Clin Rehab	cMillan et al. UK	Establish a continuous link between the patient, family and all service providers; identify and coordinate services in the hospital and community; identify needs; devise rehabilitation programs	From early post-injury through to long-term	Non-empirical	N/A	N/A	N/A	Proposes specialist dedicated brain injury CM to follow person along continuum of recovery
1991 Rehab	Whitman USA	CM serves to coordinate and integrate services, resources, communication and expectations among patient, family, treatment team and payer p.19	Inpatient rehab through to discharge	Non-empirical	N/A	N/A	N/A	Proposes a 'systems-based' model of CM
1993 Brain Inj	Goodall et al. USA	Ongoing process within the continuum of care which identifies, plans, coordinates and monitors services necessary to meet an individual's health care needs, with appropriate use of available resources and with communication among all parties concerned p.455	Inpatient, outpatient, community re-entry  Insurance company	Survey of training needs	138 CM staff	Purpose-designed survey	3 key training needs, (i) working with families (67%) (ii) vocational rehabilitation (61%) (iii) community re-entry (52%)	Specialist training is required for brain injury CM; need for certification of CMgrs in specialty areas
1994 BMJ	Greenwood et al. UK	Not defined, but outlined roles assessment; facilitate cooperation between patients, families, staff; provide information; informal counselling; organise services	Early acute hospital through to community resettlement	Prospective controlled unmatched non-randomised study	56 CM 70 control (no CM)	Physical Cognitive Functional Affect Service-related	No significant differences on any measures between CM group and non-CM group	Early provision of CM is not a substitute for provision of skilled, specialist rehabilitation
2003 Brain Inj	Fitzsimmons UK	CM aimed to manage the multiplicity of competing or complementary claims and needs – roles to identify appropriate resources, to monitor, modify and terminate input – reducing the cost to insurers – while ensuring best possible outcome for the survivor	Medium – LT post-injury 75% >2 yrs post-injury	Prospective longitudinal case series	22	N/A	N/A	Continued work by CM to reduce the handicaps consequent upon the disabilities can be effective – improvement of function is judged within view of QOL for survivors
2004 Chapter	Wood USA	CM is a collaborative process which assess, plans, implements, coordinates, monitors, and evaluates the options and services required to meet an individual's health needs using communication and available resources to promote quality cost-effective outcomes	From early post-injury through to long-term	Non-empirical	N/A	N/A	N/A	Goal of CM in TBI is to positively impact the individual's life in order to minimise long-term changes in living and occupational status, improve independence and minimise disability level
2004 Rehab Psych	Heinemann et al. USA	CM not defined, BUT comment CM purports to be effective in (i) ↓ substance use, (ii) ↑ employment, (iii) ↑ community integration, and (iv) ↑ subjective wellbeing	From outpatient (post-discharge) to long-term community	Prospective controlled unmatched non-randomised	217 CM 102 non-CM	Cog screen Add Sev. CIQ, SWLS, Fam Sat Scale, SF-36	No changes in levels of substance use; both groups ↑ community integration	Trial of substance use treatment after TBI using CM model
2005 Child: Care, Health & Dept	Scheinberg et al. Australia	Not defined, but cited ...the CM's main role in ABI is to encourage family involvement/participation in rehab, ensure appropriate education about ABI, maximise benefit (insurance) coverage, align team expectations, attend case conferences and validate treatments that are functional and outcome-oriented. (Hosack, 1999)	From early post-injury through to long-term	Prospective survey of CM roles and activities in paediatric services	40 CM staff	Purpose-designed survey	CM roles ranked in importance (i) Coordination (ii) Liaison (iii) Education (iv) Referral (v) Goal-setting (vi) Counselling (vii) Rehab plans (viii) Group work	Little research has been conducted into CM for paediatric AB

2012 Brain Impairment	Kennedy et al. Australia	Brain injury-specific CM definition: "Client-focused, collaborative, and educational practice which aims to assist clients to achieve a distinct set of goals within a specific and defined episode of the rehabilitation journey in conjunction with the treating team. This process is managed within a proactive, preventative and responsive problem-solving approach." (Royal Rehabilitation Centre Sydney, 2010, p.1)	From early inpatient through to long-term	Participatory evaluation approach (key stakeholders involved in decision-making, data collection, analysis, interpretation and implementation to inform service development & evaluation)	7 CMs 22 brain injury unit staff 3 external stakeholders	N/A Semi-structured interview	The new model was found to: – increase consistency for staff, clients and carers; – promote efficiency in discharge planning; – facilitate a more streamlined and seamless transition from inpatient to community	Proposes a comprehensive model of CM where CMgrs begin their involvement within 24hrs of inpatient admission and continue through to community rehab
2012 Brain Impairment	Lannin et al. Australia	Not defined but cites Hosack (1999): "CMgrs' main role in brain injury is to encourage family involvement and participation in rehab, ensure appropriate education about brain injury, maximise insurance coverage, align team expectations, attend case conferences and validate treatments that are functional and outcome-oriented."	Not specified	Prospective survey of CM roles and activities in adult services	51 CM staff	Purpose-designed survey of CM roles, services provided, need for PD, service evaluation models & perceived obstacles in working with TBI	Ranked perceived importance of CM components: 1. Coordination with services 2. Referral 3. Education 4. Rehab plans 5. Coordination with insurers 6. Goal-setting 7. Liaison with schools 8. Supportive counselling 9. Liaison with employers 10. Group work	Further research is needed to determine how to measure CM outcomes and the PD resources necessary for CMgrs working in ABI.

Note. Cog Screen = Neurobehavioural Cognitive Status Examination; Add Sev = Addiction Severity Index; SWLS = Satisfaction With Life Scale; Fam Sat Scale = Family Satisfaction with Life Scale.

### 9.3.3 Summary of other documentation

Other documentation of case management roles within an Australian context

#### National level

**Case Management: A framework for success.** CRS Australia, 2004

**National Standards of Practice for Case Management.** The Case Management Society of Australia. 2004, Reviewed 2013.

**National Standards of Practice Self Assessment Framework:** a resource to assist practitioners to assess their performance against the CMSA National Standards of Practice Self Assessment Framework. B. Cooper & K. Maher (Eds.). The Case Management Society of Australia. 2006.

**National Standards of Practice Self Assessment Matrix:** a resource to assist practitioners to assess their performance against the CMSA National Standards of Practice for case management. B. Cooper & K. Maher (Eds.). The Case Management Society of Australia. 2006.

#### State level

(i) New South Wales

**Case Management Feasibility Study: discussion paper.** B. Elton & Associates. Ageing and Disability Department. 1997.

**Case Management Feasibility Study: Phase 2 report.** B. Elton & Associates. Ageing and Disability Department. 1997.

**Rehabilitation for recovery: rehabilitation strategic plan NCAMHS.** R. Isaacs. 2006.

**Acquired Brain Injury Case Management: review discussion paper.** K. Stringer. Disability Services North and West Metropolitan Region. 2007.

**Case Management in the Lifetime Care and Support Scheme.** Lifetime Care and Support Authority. 2010.

(ii) Victoria

**The establishment of a health-promoting case management service: a policy process case study.** M. Summers. Centre for Health Program Evaluation.

**Evaluation of the Melbourne City Mission Acquired Brain Impairment Case Management Service.** M. Summers and L. Segal. Centre for Health Program Evaluation. 1996.

### 9.3.4 Article abstracts: Summaries from Table 4

**RESULTS:** PSYCINFO 08/04/2013

**TERMS:** 'CASE MANAGEMENT' + 'BRAIN DAMAGE' OR 'TRAUMATIC BRAIN INJURY' OR 'HEAD INJURIES'

**LIMITS:** 2010—CURRENT

**ARTICLES:** 6

1. Ashley MJ, Ashley SM. (2010). Discharge planning in traumatic brain injury rehabilitation. Ashley, Mark J [Ed]. *Traumatic brain injury: Rehabilitation, treatment, and case management*. 3rd edition. Boca Raton, FL, US: CRC Press, US; pp. 993–1036. doi:10.1201/9781439849828-c31.

TBI has the potential to visit upon an individual tremendous change and, in some cases, devastation to life as it might have been known to the person prior to injury. Although professionals struggle to find better ways to mitigate the effects of brain injury, treatment must ultimately come to an end. When it does, the fruits of the discharge planning process become more or less apparent. Discharge planners faces tremendous challenges at all levels of care, not the least of which is developing a firm understanding of the broad impact of brain injury upon the person. The purpose of this chapter is twofold: to offer a broadened view of discharge planning that extends years beyond injury and to provide insights into the nature of the long-term problems encountered, with methods of addressing these problems. Much of the discussion in this chapter involves post-discharge caregivers, their needs, concerns, and education. This chapter approaches the issues from the perspective of what can be done within current limitations of the managed care environment.

2. Ashley MJ [Ed]. (2010). *Traumatic brain injury: Rehabilitation, treatment, and case management*. 3rd edition. Boca Raton, FL, US: CRC Press, US; doi:10.1201/9781439849828.

(From the cover) Since the bestselling second edition was published almost a decade ago, the field of brain injury treatment has undergone tremendous change, largely impacting access to treatment. However, while the healthcare marketplace has evolved, the needs of brain injury victims remain the same. With updated and expanded clinical coverage, *Traumatic brain injury: Rehabilitation, treatment, and case management*, Third edition delineates a broad spectrum of advanced theoretical clinical constructs and detailed diagnostic

and treatment interventions for traumatic brain injury. With contributions from more than 50 authorities in both academia and industry, this highly respected text stands apart as a clinical guide to rehabilitative treatment of persons with traumatic brain injury following the acute phase of treatment. It provides a concise source of information about the scientific and therapeutic realms involved in the rehabilitation of a person with traumatic brain injury, specifically as they relate to persistent deficits. The book also details long-term consequences of brain injury and effective approaches to vocational rehabilitation and case management. Widening coverage from the previous edition, this book includes details on: (a) Metabolic and bioenergetic factors in brain injury; (b) Neuroendocrine dysfunction following brain injury; (c) Blast injury; (d) Ethical issues in treatment of brain injury; (e) Neuropharmacological and neuropsychological interventions following brain injury; (f) Interventions for the minimally conscious patient; and (g) Dietary and exercise considerations after brain injury. *Traumatic brain injury: Rehabilitation, treatment, and case management*, Third edition is a complete source of pharmacological, anatomical, and physiological information for basic therapeutic rationales that are often not well understood in the field. It is an ideal reference for both new and experienced clinicians.

3. Kapapa T, Konig K, Pfister U, Sasse M, Woischneck D, Heissler H, et al. (2010). Head trauma in children, part 2: Course and discharge with outcome. *Journal of Child Neurology*, 25;274–283. doi:10.1177/0883073809332699.

To minimise the secondary brain damage, we analysed the effect of cerebral perfusion pressure-orientated management and tried to find factors of clinical management and biochemical findings that influence clinical, cognitive, and psychosocial outcome. Management at intensive care unit was standardised. A standardised (short form 36 health survey) and nonstandardized split questionnaire explored long-term outcome. Glutamic-oxaloacetic-transaminase, creatine kinase MB or glucose are markers for bad outcome ( $P < .05$ ). Patients with cerebral perfusion pressure values below the recommended standard for just a single occurrence had significantly worse outcome ( $P = .0132$ ). Mean arterial pressure, central venous pressure, and heart rate alone do not correlate with outcome. At least one occurrence of mean arterial pressure and central venous pressure below the lower

limits resulted in a poor outcome ( $P = .035$ ). Cerebral perfusion pressure-guided therapy seems to prevent further brain damage and results in outcome scores that are comparable to those children with head trauma exhibiting symptoms of mild brain edema.

4. Kennedy N, Barnes J, Rose A, & Veitch C. (2012). Clinicians' expectations and early experiences of a new comprehensive rehabilitation case management model in a specialist brain injury rehabilitation unit. *Brain Impairment*, 13;62–71. doi:10.1017/BrImp.2012.2.

This article presents early findings from the implementation and ongoing evaluation of a new model of care that employs a comprehensive approach to rehabilitation case management for clients with traumatic brain injury, with the aim of improving transition from inpatient rehabilitation to community settings. The evaluation explores the design, implementation, utility and acceptability of the new model using clinicians' perceptions and experiences. Method: The evaluation framework employs a participatory evaluation approach, drawing on semistructured interview data. Interviews were conducted with brain injury unit clinicians, rehabilitation case managers and external stakeholders at the model's implementation and four months later, as part of a 12-month evaluation period. The data were descriptively organised, then coded and subjected to interpretative analysis to identify key issues. Results: Early findings suggest that the new model provides increased consistency for staff, clients and carers; promotes efficiency in discharge planning and facilitates a more streamlined and seamless transition between inpatient rehabilitation and community services. Data gathered across the remainder of the implementation trial will extend understanding of this comprehensive rehabilitation case management model and its potential utility in other services and settings.

5. Lannin N, Henry K, Turnbull M, Elder M, Campisi J. (2012). An Australian survey of the clinical practice patterns of case management for clients with brain injury. *Brain Impairment*, 13;228–237. doi:10.1017/BrImp.2012.19.

Aim: To investigate the characteristics of Australian organisations providing case management to individuals who have acquired brain injury, and to determine the methods of case management service delivery including professional development and evaluation of outcomes. Method: An anonymous 23-item web-based survey was used. Respondents were case managers who deliver services to adults and/or children with brain injuries. A snowball sampling method was used to recruit respondents from around Australia. Findings: Fifty-one case managers completed the survey. Respondents were from a wide range of professions, the largest group being occupational therapy. The majority of respondents were based in metropolitan areas, were employed within the public health system and were based in the community. Respondents reported that the main determinant for clients receiving case management was the severity of the brain injury followed by complex family needs. Variations in practice and a lack of consistency in outcome measurement, goal setting and professional development were noted. Discussion: This study provides an overview of characteristics of case management practices for people with ABI. Identifying roles and responsibilities of case managers is the first step to developing future research designs, which determine the effectiveness of case management.

6. Wood J. (2010). External case management of brain injury: An overview. Ashley, Mark J [Ed]. *Traumatic brain injury: Rehabilitation, treatment, and case management*. 3rd edition. Boca Raton, FL, US: CRC Press, US; pp. 913–931  
doi:10.1201/9781439849828-c28.

(from the chapter) The case manager carries on a delicate balance of meeting the needs of the traumatic brain injury (TBI) person and meeting the needs of all other parties involved. It is not uncommon for financial or legal parties, in particular as referral sources, to wield significant pressures for the case manager to utilise specific approaches to the rehabilitation process. The case manager must carefully evaluate the influence of all motivators on decisions of a case. The primary rule of thumb to be followed is that if the injured individual will gain substantial benefit from a particular treatment, all other parties will benefit. The temptation may be present to lean in the direction of a plaintiff or defense attorney, for example, or in the direction of a parent or spouse. However, the case manager must be able to maintain a neutral high ground that focuses on the needs of the injured individual first considering the needs and desires of others secondarily. The goal of the case manager in a brain injury case is to impact the individual's life positively to minimise long-term changes in living and occupational status, and to improve independence and minimise disability level. All goals should support each other and must be congruent with each other. The case manager is the individual's advocate, who speaks for that individual across teams and disciplines to keep the decision makers focused. As the rehabilitation process proceeds, case managers should broaden their role and help injured individuals and their family advocate for themselves. The case manager is an integral part of the rehabilitation process and, as such, has a responsibility to enhance the overall process. Good, thorough rehabilitation is a winning scenario for society, the funding sources, the family, the case manager, and, most important, the person with TBI.

**RESULTS:** CINAHL ON 08/04/2013

**TERMS:** 'CASE MANAGEMENT' + 'BRAIN INJURIES' OR 'HEAD INJURIES'

**LIMITS:** 2010-2013

**ARTICLES:** 15

1. Adams RS, Corrigan JD, Larson MJ. (2012). Alcohol use after combat-acquired traumatic brain injury: What we know and don't know. *Journal of Social Work Practice in the Addictions*, 12:28–51.

Military personnel engage in unhealthy alcohol use at rates higher than their same-age civilian peers, resulting in negative consequences for the individual and jeopardized force readiness for the armed services. Among those returning from combat deployment, unhealthy drinking might be exacerbated by acute stress reactions and injury, including traumatic brain injury (TBI). Combat-acquired TBI is common among personnel in current conflicts. Although research suggests that impairment due to TBI leads to an increased risk for unhealthy drinking and consequences among civilians, there has been little research to examine whether TBI influences drinking behaviours among military personnel. This article examines TBI and drinking in both civilian and military populations and discusses implications for clinical care and policy.

2. French, LM, Parkinson GW, Massetti S. (2011). Care coordination in military traumatic brain injury. *Social Work in Health Care*, 50:501–514.

Traumatic brain injury (TBI)-an injury to the brain that may or may not create lasting impairment for the survivor-has been recognised as a major public health problem by the Centers for Disease Control (Langlois, Rutland-Brown, & Thomas, 2006). Ongoing conflicts in Iraq and Afghanistan have highlighted the problem for the military (Warden, 2006). Many soldiers are exposed to severe impact to the head resulting in TBI. As those with TBI transition to their home locality, civilian social workers and other providers will be involved in their care. This article examines the medical and emotional implications of mild TBI and offers suggestions for care of those affected, both the service member and his/her family.

- Amdur D, Batres A, Belisle J, Brown JH, Cornis-Pop M, Mathewson-Chapman M, Harms G, Hunt SC, Kennedy P, Mahoney-Gleason H, et al. (2011). VA Integrated Post-Combat Care: A Systemic Approach to Caring for Returning Combat Veterans. *Social Work in Health Care*, 50:564–575.

The Department of Veterans Affairs (VA's) mission is to care for those who have borne the battle. As medical technology has advanced, more and more of our returning combat veterans survive what would have been fatal wounds in previous conflicts (Gawande, 2004). But survival is only the immediate goal—our job is to restore veterans to the greatest level of health, independence, and quality of life that is medically possible. The VA is achieving this goal through close collaboration with the Department of Defense (DoD) to facilitate a smooth transition and continuum of care that ensures veterans and service members receive the care they deserve. This article describes VA's system of Veteran-centred, post-combat care programs that rely on significant involvement of social workers to support service members, veterans and their families through recovery, rehabilitation, and reintegration into their home communities.

- Lewis FD. (2011). Ethics in case management: making the right decision in tough times. *Care Management*, 17:10–13, 20–21.

A morally sound framework from which to address ethical issues will help the case manager to reduce the stress of difficult decision-making and lead to better resolutions. The author adapts Arthur Anderson's Seven Step Model for Moral Reasoning as a framework for making ethical decisions. He then applies the model to a case example to give case managers the tools they need in everyday practice.

- Cooley SG, Asthana S. (2010). Dementia care for veterans: enhancing comprehensive, coordinated services. *Generations*, 34:57–63.

No abstract.

- Pieroth EM. (2012). Managing the return to work issues after a concussion. *Professional Case Management*, 17:141–142.

No abstract.

- Arabi YM, Haddad S, Tamim HM, Al-Dawood A, Al-Qahtani S, Ferayan A, Al-Abdulmughni I, Al-Oweis J, Rugaan A. (2010). Mortality reduction after implementing a clinical practice guidelines-based management protocol for severe traumatic brain injury. *Journal of Critical Care*, 25:190–195.

**Introduction:** The objective of this study was to examine the effect of implementing a clinical practice guidelines-based management protocol on the outcome of patients with severe traumatic brain injury (TBI). **METHODS:** We carried out a pre-post guideline implementation study using previously collected data in the Intensive Care Unit (ICU). All patients older than 12 years with severe TBI, defined as a Glasgow Coma Scale score of 8 or less, from March 1999 to January 2001 (control group) and from February 2001 to December 2006 (protocol group) were identified and included in this study. Patients in the protocol group were managed using a clinical practice guidelines-based management protocol, derived from the guidelines published by the Brain Trauma Foundation. Primary outcome was hospital mortality, whereas the secondary outcome was ICU mortality. To assess whether the ICU protocol might have led to an increase in the number of surviving patients with severe disability, we examined the association of the protocol use and the need for tracheostomies, mechanical ventilation duration, and ICU and hospital length of stay among survivors. **RESULTS:** During the study period, a total of 434 patients met the inclusion criteria. After adjustment for several prognostic factors, the use of protocol was independently associated with a significant reduction in hospital and ICU mortality (odds ratio, 0.45; 95% confidence interval, 0.24-0.86; and odds ratio, 0.47; 95% confidence interval, 0.23-0.96, respectively). The use of the protocol was not associated with an increase in the need for tracheostomies, mechanical ventilation duration, ICU LOS, and hospital LOS. **CONCLUSION:** The protocol implementation was associated with a reduction in hospital and ICU mortality. This improvement was not associated with an increase in the frequency of tracheostomies and in ICU or hospital LOS, suggesting that the improved survival was not associated with the increased number of surviving patients with severe disability and that the functional status might have also improved.

8. Ashley MJ, Connors SH. (2010). Managing patients with traumatic brain injury across a long and often difficult continuum of care. *Care Management, 16*:7–10, 27.

For patients, TBI is not an event or an outcome but the start of a lifelong disease process. By keeping the endpoint in mind, case managers must identify and marshal the resources that will facilitate achievement of the patient's true potential, including medical and rehabilitative treatment that is available, accessible, appropriate, and affordable given the patient's health status, individual or family preferences, current physical location, and medical insurance policies or other third party payer limitations.

9. Martin EM, French L, Janos A. (2010). Home/ community monitoring using telephonic follow-up. *NeuroRehabilitation, 26*:279–283.

Service members who have had a traumatic brain injury (TBI) in a war theatre [Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF)] may have associated injuries far different and/or more complex (i.e., polytrauma) than injuries obtained outside the theatre of operation. This article expands on what has been learned from monitoring patients injured during peacetime to the newly injured war veterans being monitored in the home setting via routine telephonic follow-up. As Tanielian et al. state TBI, post-traumatic stress disorder (PTSD) and major depression may occur during and following deployment/s which then pose a significant health risk to these veterans. This is particularly important as veterans of these two conflicts may incur these "invisible wounds of war". Thus, safe and effective monitoring of these veterans by nurses/ case managers in the home/ community setting becomes important in the recovery process.

10. Palsbo SE, Diao G. (2010). The business case for adult disability care coordination. *Archives of Physical Medicine & Rehabilitation, 91*:178–183.

**Objective:** To analyse the financial performance of a care coordination program.

**Design:** The study used a retrospective pre-test, post-test design of 245 beneficiaries. Physical impairment ranged from slight to severe.

**Setting:** Minnesota Disability Health Options (MnDHO), a capitated Medicaid program.

**Participants:** Medicaid beneficiaries ages 18 to 64 with physical disabilities arising from multiple sclerosis, cerebral palsy, spinal cord injury, or brain injury.

**Interventions:** Not applicable.

**Main Outcomes Measures:** Change in expenditures, rate of return, and utilisation.

**Results:** Mean MnDHO monthly expenditures including care coordination increased by a factor of 1.75 ( $P < .001$ ) over the previous expenditures. Increasing age has a multiplier effect on increased expenditures. Hospitalization rates were unchanged, but the average cost per admission and average length of stay dropped significantly ( $P = .017$ ,  $P = .032$ , respectively). For people enrolled at least 3 years, annual reductions in medical costs more than paid for the added cost of care coordination, but the savings in Year 3 were about 20% of the savings in the first 2 years.

**Conclusions:** Care coordination leads to higher program expenditures for enrollees with moderate physical impairments who encounter access problems, but has little impact on enrollees who are already getting 24-hour care. There is some evidence of adverse selection bias. MnDHO's disability care coordination may not be financially sustainable over the long term.

11. Smallfield A, Evans T, Bhimani M. (2010). Neck injury at a rural emergency department: perils, pitfalls and management considerations. *Canadian Journal of Rural Medicine*, 15:120–122.

No abstract.

12. Pieroth EM. (2010). Is specialized care required for concussive injuries? *Professional Case Management*, 15:47–49.

No abstract.

13. Turnball M, Henry K, Elder M, Campisi J, Lannin N. (2011). Clinical practice patterns of case management for people with brain injury: a national survey of case managers... Occupational Therapy Australia, 24th National Conference and Exhibition, 29 June - 1 July 2011. *Australian Occupational Therapy Journal*, 58 Supplement:17.

No abstract.

14. CEU for CMM & CDMS. (2010). *Care Management* 16:16–17.

No abstract.

15. MacDonell CM. (2010). News from CARF. Setting the international standards for acquired brain injury providers. *Care Management*, 16:5, 28.

No abstract.

## 9.4 Appendix 4: Domains of interest to measuring case management

Table 7: Domains of interest to measuring case management outcome for adult BIRP clients grouped according to the WHO ICF

Impairment (body structure/function)	Clinical indicators	Outcome measures	Process indicators
Physical health Comorbidities (mental health) Ability to deal with stress Cognitive processes Law breaking Sense of belonging Knowledge of TBI Fatigue Epilepsy	Accessing drug and alcohol services Accessing psychiatrist/psychologist Medications Symptom checklist	MPAI-IV CANS Health of the Nation Outcome Scale for ABI Overt behaviour scale QOL measure	CM activity form Service satisfaction LOS / OOS Service readmissions Unmet versus met needs
<b>Activity</b>			
Adjustment to injury Self-management/compensatory activities Decision-making Autonomy and independence Sense of security/safety Income and resources Independent living skills Goal-directed behaviour Goal management		MPAI-IV CANS Knowledge and use of compensatory devices/strategies	
<b>Participation</b>			
Leisure Study, work Relationships	Australian Bureau of Statistics Time Use Survey Occupation (Return to work scale)	MPAI-IV MOSS Tool CANS SPRS Nottingham Leisure Scale	
<b>Environment</b>			
Family relationships Community development/address service gaps Education service networks Service access/support	Housing stability	MPAI-IV Service Obstacles Scale Carer burden scales CANS MOSS Tool Sydney Psychosocial Reintegration Scale	

Tool	Reference
MPAI-IV	<p><b>Mayo-Portland Adaptability Inventory</b></p> <p>Malec, J. (2005). The Mayo-Portland Adaptability Inventory. <i>The Center for Outcome Measurement in Brain Injury</i>.  <a href="http://www.tbims.org/combi/mpai">http://www.tbims.org/combi/mpai</a></p>
HONOS ABI	<p><b>Health of the Nation Outcome Scale for ABI</b></p> <p><a href="http://www.rcpsych.ac.uk/crtu/healthofthenation/acquiredbraininjury.aspx">http://www.rcpsych.ac.uk/crtu/healthofthenation/acquiredbraininjury.aspx</a></p>
OBS	<p><b>Overt Behaviour Scale</b></p> <p>Kelly, G. (2010). The Overt Behaviour Scale. <i>The Center for Outcome Measurement in Brain Injury</i>.  <a href="http://www.tbims.org/combi/obs">http://www.tbims.org/combi/obs</a></p>
QOL measures	<ol style="list-style-type: none"> <li>QOLIBRI Quality of Life after Brain Injury  <a href="http://www.qolibrinet.com/registration.htm">http://www.qolibrinet.com/registration.htm</a>  von Steinbüchel, N., Wilson, L., Gibbons, H., Hawthorne, G., Höfer, S., Schmidt, S., et al. (2010b). Quality of Life after Brain Injury (QOLIBRI): Scale development and metric properties. <i>Journal of Neurotrauma</i>, 27, 7, 1167-1185.</li> <li>WHOQOL-BRIEF  <a href="http://www.who.int/substance_abuse/research_tools/whoqolbref/en/">http://www.who.int/substance_abuse/research_tools/whoqolbref/en/</a></li> <li>Neuro-QOL (PROMIS)  <a href="https://www.assessmentcenter.net/ac_content/Register/437259A7-7124-4D97-8817-C8AC8090D7AC">https://www.assessmentcenter.net/ac_content/Register/437259A7-7124-4D97-8817-C8AC8090D7AC</a></li> <li>The Life Satisfaction Questionnaire 9 (LiSAT-9)  A copy of the LISAT-9 appears in: Anke, A. G. W. and A. R. Fugl-Meyer (2003). Life satisfaction several years after severe multiple trauma—a retrospective investigation. <i>Clinical rehabilitation</i> 17(4): 431.</li> </ol>
MOSS Tool	<p><b>Measuring Outcomes of Services and Supports (MOSS) Tool</b></p> <p>Richmond, Kelli Nicola, Wilson, Erin, Hagiliassis, Nick and Mackay, Anne. 2011. <i>Summary sheet: measuring outcomes in services and supports (MOSS) tool</i>. Scope (Vic) Ltd., Box Hill,Victoria.  <a href="http://dro.deakin.edu.au/view/DU:30042069">http://dro.deakin.edu.au/view/DU:30042069</a></p>
SPRS	<p><b>Sydney Psychosocial Reintegration Scale</b></p> <p>Tate, R.L. (2011) Manual for the Sydney Psychosocial Reintegration Scale version 2 (SPRS-2). Unpublished Manuscript, Rehabilitation Studies Unit, University of Sydney.</p>
Nottingham Leisure Scale	<p>Drummond AE<sup>1</sup>, Parker CJ, Gladman JR, Logan PA; TOTAL Study Group. Development and validation of the Nottingham Leisure Questionnaire (NLQ). <i>Clin Rehabil</i>. 2001 Dec;15(6):647-56.</p>
CANS	<p>Tate, R.L. (2011) Manual for the Care and Needs Scale (CANS). Unpublished manuscript, Rehabilitation Studies Unit, University of Sydney. Revised version 1.  <a href="http://www.lifetimecare.nsw.gov.au/_data/assets/pdf_file/0019/18415/Care_and_Needs_Scale_Manual_2011.pdf">http://www.lifetimecare.nsw.gov.au/_data/assets/pdf_file/0019/18415/Care_and_Needs_Scale_Manual_2011.pdf</a></p> <p>Tate RL. (2004) Assessing support needs for people with traumatic brain injury: the Care and Needs Scale (CANS). <i>Brain Inj</i>. 2004 May;18(5):445-60.</p>
SOS	<p><b>Service Obstacles Scale</b></p> <p>Kreutzer, J. (2000). The Service Obstacles Scale. <i>The Center for Outcome Measurement in Brain Injury</i>.  <a href="http://www.tbims.org/combi/sos">http://www.tbims.org/combi/sos</a></p>
Caregiver burden scale	<ol style="list-style-type: none"> <li>Zarit Steven H. Reever, Karen E., Bach-Peterson, Julie (1980). Relatives of the Impaired Elderly: Correlates of Feelings of Burden (Caregiver Burden Scale) <i>The Gerontologist</i> (1980) 20 (6): 649-655.</li> <li>Macera, C.A., Eaker, E.D., Jannarone, R.J., Davis, D.R., Stoskopf, C.H. (1993). A Measure of Perceived Burden among Caregivers. <i>Evaluation &amp; the Health Professions</i> 16 (2), 204–211.</li> </ol>

## 9.5 Appendix 5: Profile of BIRP case managers

A case manager profile was developed in consultation with adult and paediatric clinicians from written information derived from position descriptions and recruitment processes.

The five agreed areas of competency are clinical skills, knowledge, experience, attitude and qualifications.

The purpose of this profile is to assist in the development of position descriptions, recruitment processes,

professional development and identifying gaps in skills for the individual and for the case management service.

### Clinical skills

- Specialised skills for working with adults/ paediatric populations with complex brain injuries and their families, including education, assessment, goal-setting, planning, implementing and evaluating client-based services
- Skills in recognising dual disabilities and helping clients to access appropriate resources
- Superior interpersonal skills to establish rapport and liaison with adults/children and young people with traumatic brain injuries, their families and other professionals in a variety of settings
- Ability to identify competing, complex client and family issues/needs/goals
- Skills in working autonomously with minimal direct clinical supervision on a day-to-day basis
- Skills in applying independent professional knowledge and judgement when providing services to clients and their families, particularly given the complex nature of the impact of brain injuries on clients and their families
- Effective teamwork skills and ability to work across teams
- Skills in effective liaison with other team members, medical specialists, insurers/funders and other external organisations
- Advanced clinical reasoning, reflection and problem-solving skills
- High levels of initiative and self-direction
- Skills in gathering, analysing and synthesising evidence from research, clients, their families and other sources to provide high-quality evidence-based, goal-directed service planning
- Skills to engage in quality improvement projects relevant to adults/paediatric populations with a brain injury
- Skills in providing clinical in-services to staff and students for educational purposes
- Skills in providing consultation to staff employed by other organisations relevant to adults/ paediatric populations with complex brain injuries and therapy programs
- Presentation skills for group work and education sessions
- Excellent verbal and written communication
- High level of competency in computer use
- High-level organisation and time-management skills.

## Knowledge

- Advanced knowledge of the principles, procedures and techniques involved in providing effective rehabilitation case management programs for adult/paediatric populations with complex brain injuries
- Up-to-date knowledge of research, particularly traumatic brain injury research, relevant to adult/paediatric populations with complex brain injuries
- Up-to-date knowledge of the complex short- and long-term impact of complex brain injuries on adult/paediatric populations
- Knowledge of strategies to promote effective teamwork and liaison
- Extensive knowledge of the terminology, mechanisms of injury, treatment, recovery, rehabilitation and prognosis in TBI
- Broad current knowledge of health-related issues
- Rights and responsibilities of clients of the service
- Extensive current knowledge of community resources
- Awareness/knowledge of the relevant legislative frameworks.

### Relevant legislative frameworks could include:

- World Health Organization International Classification of Function
- *Disability Services Act 1993* (NSW)
- *Occupational Health and Safety Act 2000* (NSW)
- *Social Security Act of 1991* (Commonwealth)
- *Guardianship Act 1987* (NSW)
- *Victims Support and Rehabilitation Act 1996* (NSW)
- *Working with Children Legislation (Children and Young People act) 1998* (NSW)
- *Mental Health Act 2007* (NSW)
- *Motor Accidents Act of 1999* (NSW)
- *Life Time Care and Support Act of 2006* (NSW)
- *Workplace Injury Management and Workers Compensation Act 1998* (NSW).

## Experience

- Provision of comprehensive rehabilitation case management services relevant to adults/young people and children with brain injuries and their families
- Working effectively in teams
- Advanced knowledge of the principles, procedures and techniques involved in providing effective rehabilitation case management for complex clients
- Up-to-date knowledge of research, particularly TBI research, relevant to clients with complex brain injuries
- Up-to-date knowledge of the complex short- and long-term impact of complex brain injuries on adult/ paediatric populations
- Knowledge of strategies to promote effective teamwork and liaison
- Extensive knowledge of the terminology, mechanisms of injury, treatment, recovery, rehabilitation and prognosis in TBI
- Broad current knowledge of health-related issues
- Rights and responsibilities of clients of the service
- Extensive current knowledge of community resources
- At least two years of experience in allied health
- A minimum of three years of experience in paediatrics with experience in either paediatric or adult neurorehabilitation.

## Attitudes

- Demonstrate respect for all clients, family members and other team members
- Value the opinions and contributions of clients, family members and other team members
- Ensure the individual client's dignity is maintained at all times
- Culturally sensitive practice for Aboriginal and Indigenous people and people from a non-English-speaking background.

## Qualifications

- Degree in allied health or related field, such as nursing, occupational therapy, speech pathology, social work, physiotherapy or psychology
- Eligibility for membership of professional association, if appropriate/eligibility for membership to relevant allied health national association
- Meet criteria for Allied Health Award level 3 or equivalent
- Current drivers' licence.

Recruiting the right person for BIRP case manager positions is a process of continuous performance review and professional development. In addition, case management for adults of working age, young people and children admitted to BIRP services can be complex, demanding and stressful. It is therefore also important for supervisors to manage the caseload of BIRP case managers so work output meets expectations and stress and burnout is avoided.

It was determined that further research was required to develop and trial workload management tools to achieve consistency in implementation and use across adult and paediatric BIRP community rehabilitation teams.

