NSW Agency for Clinical Innovation

## NSW Brain Injury Rehabilitation Directorate

# FEEDBACK REGARDING THE PRODUCTIVITY COMMISSION DRAFT REPORT REGARDING THE NATIONAL DISABILITY INSURANCE SCHEME

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# *CONTEXT OF SUBMISSION:*

## *The Needs of People with Brain Injury in NSW*

## 1. INTRODUCTION

The Agency for Clinical Innovation (ACI) Brain Injury Rehabilitation Directorate (BIRD) unites the network of 14 individual services that comprise the NSW Brain Injury Rehabilitation Program (BIRP).

The BIRD welcomes the opportunity to provide feedback regarding the Disability Care and Support Report published in February 2011. The aim of the National Disability Insurance Scheme (NDIS), and National Injury Insurance Scheme (NIIS), to provide universal disability and care services for people with disability in Australia is laudable. The BIRD supports the principles of a national scheme that targets the needs of consumers rather than isolating people with disability on the basis of diagnosis.

In NSW insurance has made a difference for people with disability from motor vehicle crashes and provides a model to inform national developments. The introduction of the Lifetime Care and Support Scheme (LTCS) in October 2006 has increased the scope of services available to people of all ages who sustain their brain injury from motor vehicle accidents in NSW. However there is a large gap in service provision for people who sustain traumatic injuries by other means (e.g. falls) or from non traumatic causes (e.g. stroke, infections). The National Disability Scheme seeks to address that gap to improve the equity of access and outcome for all people with disabilities.

The BIRD focus on delivering co-ordinated rehabilitation for people with acquired (primarily traumatic) brain injury to minimise the resultant changes in physical, communication, cognitive, behaviour and psychosocial functioning, and the ability to participate in our community including social relationships, meaningful leisure and work activities.

This response is divided into two sections. First, the background to brain injury related disability and rehabilitation services will be described. This identifies the current situation and provides the context for feedback on the actual report that follows in the second part of this submission.

### 1.1 Prevalence and Cost of Brain Injury in Australia

Acquired brain injury (ABI) includes damage to the brain sustained after birth and includes traumatic brain injuries (TBI) and non traumatic injuries (Teasell, Bayona, Marshall, Cullen, Bayley, Chundamala, Villamere, Mackie, Rees, Hartridge, Lippert, Hilditch, Welch-West, Weiser, Ferri, McCabe, McCormick, Aubut, Comper, Salter, Van Reekum, Collins, Foley, Nowak, Jutai, Speechley, Hellings, Tu, 2007). ABI is often thought of as having a low incidence but a high cost to the individual, their family and friends and to society as a whole. However ABI is common and is one of the major causes of significant disability and death in Australia [AIHW, 2003b; Teasell, Bayona, Marshall, Cullen, Bayley, Chundamala, Villamere, Mackie, Rees, Hartridge, Lippert, Hilditch, Welch-West, Weiser, Ferri, McCabe, McCormick, Aubut, Comper, Salter, Van Reekum, Collins, Foley, Nowak, Jutai, Speechley, Hellings, Tu, 2007] with 1 in 45 Australians having an ABI with activity limitations or participation restrictions [AIHW, 2003b]. People who sustain moderate or severe brain injuries are more likely to need lifelong care and support. In 2008 the estimated incidence of new brain injury is 1,493 new cases of moderate TBI and 1,000 new cases of severe TBI based on 2008 data (Access Economics, 2009). The incidence of moderate to severe traumatic brain injury is 5480, compared to other diagnostic groups including cerebral palsy (22,792), and bipolar disorder (99,099) but the cost is much greater (9.5 billion versus 3.9 and 1.6 billion dollars respectively). These figures do not include ABI from other causes (e.g. stroke).

Brain injury often strikes people who are young and school or working age. Almost three quarters of all people with acquired brain injury, and almost all who have brain injury as their main disabling condition, are under 65 years [AIHW, 2003b]. Two thirds of those acquired their injuries when aged less than 25, with a strong peak in incidence in males aged 15-24 [AIHW, 2003b]. Thus, the most disabling of brain injuries affect young people, and cause pervasive and lifelong disability that affects multiple areas of physical, cognitive, behavioural and social functioning.

The cost of TBI is enormous. “The total cost of TBI in Australia was estimated to be $8.6 billion, of which $3.7 billion are attributable to moderate TBI and $4.8 billion to severe TBI (See Table 1) (Access Economics, 2009). These costs include financial and burden of disease costs. The lifetime costs per incident case of TBI were estimated to be $2.5 million and $4.8 million respectively for moderate TBI and severe TBI (Access Economics, 2009)

**Table 1:** Direct Health and Disability Costs for Moderate end Severe Traumatic Brain Injury (Access Economics, 2009)

| COSTS | Moderate TBI | Severe TBI |
|---|---|---|
| **Health** | $269.1 million | $308 million |
| **Aids and Equipment** | $59.7 million | $158.5 million |
| **Care** | $300 million | $ 962.5 million |

Although health care costs usually decrease over the first 6 years post injury the long term costs associated with care and accommodation increase during this time. These costs are often hidden, as many people with TBI don’t access disability services because the type of service available is insufficient or unable to meet their needs. There are also enormous costs associated with caring for people with brain injury. The total lifetime carer costs in Australia are approximately $25.1 million for people with moderate TBI and $28.5 million for people with severe TBI = $28.5 TBI (Access Economics, 2009). The cost is high for both individual people with brain injury and their carers, plus to the Australian community. This information is significant when designing a National Disability Scheme as it provides indicators of cost and more importantly, support the need for a Scheme that provides the infrastructure to manage growth and deliver efficient and effective services and highlights the need to collaborate with existing insurers so that all people with disability have access to the services they need to achieve social inclusion.

## 1.2 Impact of TBI on Functioning

Regardless of aetiology, the location and extent of damage to the brain will result in a complex mix of impairments, disabilities and participation restrictions (Khan, Baguley, and Cameron, 2003; Teasell, Bayona, Marshall, Cullen, Bayley, Chundamala, Villamere, Mackie, Rees, Hartridge, Lippert, Hilditch, Welch-West, Weiser, Ferri, McCabe, McCormick, Aubut, Comper, Salter, van Reekum, Collins, Foley, Nowak, Jutai, Speechley, Hellings, Tu, 2007). Impairments can include reductions in cognitive, physical, emotional, behavioural and sensory functioning. TBI can affect many different aspects of a person's life and change life goals as most people with TBI are not able to recover to pre injury levels of functioning or access the services and support essential to achieve positive life changes. After brain injury tremendous changes in functioning at the activity and participation level typically occur. Many people with brain injuries spend the majority of their time engaged in passive or solitary activities, resulting in 'uninvolved' and unsatisfactory lifestyles" (McCabe, Lippert, Weiser, Hilditch, Hartridge, Villamere, 2007). Consequences of brain injury can include disruption to people's independence, interpersonal relationships, and ability to engage in leisure and productive activities (Marsh and Kersel, 2006). The mechanisms and recovery from brain injury are complex and no two brain injuries are the same (Ragnarsson, 2002; Willer and Corrigan, 1994).

## 1.3 Access to Rehabilitation and Care for People with Brain Injury in NSW

### 1.3.1 The NSW Brain Injury Rehabilitation Programme

A distinctive feature of brain injury rehabilitation within NSW is the co-ordinated network of services that provide specialist rehabilitation services within a decentralised structure across the state. This network is known at The NSW Brain Injury Rehabilitation Program (BIRP). This program was established in 1989 as a joint initiative between the NSW Department of Health and the Motor Accidents Authority of NSW. The state-wide network of Brain Injury rehabilitation programs in NSW currently comprise 14 centres (11 adult services and 3 dedicated paediatric services) which provide a comprehensive range of rehabilitation services. The NSW BIRP provides inpatient, transitional and community services. Five of the BIRP services are located in Sydney (3 adult and 2 paediatric) and eight of which are located in regional centres and provide outreach services to rural areas. Each program offers a different range of rehabilitation services (inpatient, outpatient, transitional living, community based and outreach) according to the needs of their geographical region and client populations.

In line with Corrigan's (2001) recommendations, the NSW network of brain injury rehabilitation services provide comprehensive and co-ordinated services for clients with varying needs around the state. People have access to expert service close to their own communities and they are supported through the difficult process of re-entering their family and community life after a severe injury. The brain injury rehabilitation services in NSW (and elsewhere) differ in terms of structure, scope, organisation and philosophy, that reflects differences in funding streams, the matrix of other local services and perceived needs of people with brain injury in the local area (Corrigan, 2001; Enderby & Wade, 2001; Velema and Cornielje, 2003; GMCT BIRD, 2004; Hopman, 2005). However all the NSW services aim to be responsive to the needs of local people and accommodate the diversity of problems after brain injury (Corrigan, 2001).

The BIRP network operates to some extent on a hub and spoke model. Those with most severe injuries will have impatient care provided at a major trauma centre, followed by specialist inpatient rehabilitation. After inpatient rehabilitation patients are usually discharged to the care of the local BIRP service. There are eight transitional living units within the network that provide residential rehabilitation as people transition from hospital to home, and where there are greater needs after people have been living in the community for some time.

The BIRD manages a network data system regarding access and outcomes from the BIRP. The database has been custom designed to reflect the needs of people with brain injury and how services are delivered within the BIRP. Each BIRP service submits electronic demographic and clinical data to BIRD to enable state-wide reporting. This supports robust data regarding client characteristics and service demands across the state. NSW BIRP has strong focus on research and aims to provide evidence base to support service development through systematic objective outcome data.

### 1.3.2 The NSW Agency for Clinical Innovation ACI Brain Injury Rehabilitation Directorate

The Brain Injury Rehabilitation Directorate (BIRD) was established by ACI as a clinical network in 2002 and utilises the existing network of brain injury rehabilitation services that make up the NSW BIRP to identify issues of importance across the state and how and where improvements are needed for delivering safer and better care. Incorporating research and evidence based practice into the clinical services available in the NSW BIRP provides the opportunity to generate, disseminate and promote new knowledge to improve options for people living with disability after TBI and their families. Key roles of the BIRD are to co-ordinate research and clinical data. The BIRD has established a data collection system that receives data from all BIRP services and identifying and using appropriate measures of outcome are the key areas of activity for the BIRD. Key lessons from the experience of the BIRD are relevant to the proposed NDIS and NIIS:

- Research needs to be coordinated and prioritised- identify key issues by involving consumers, clinicians and identify gaps in knowledge to establish areas of priority for research. The BIRD increasingly involves clinicians in the NSW BIRP to complete state-wide research projects and seeks national collaboration for robust outcomes – this model could be expanded nationally and for other disability groups.
- Research tools need to be robust and provide the information needed to ensure that the information collected is useful for the identified purpose. Refer to Appendix 2 for a review of the I-Cans
- Research and data collection needs to be supported. The NSW BIRP employs a full time data and information manager to support administrative and clinical staff to enter accurate data, use their data locally and increase their knowledge and understanding of how research can make a difference in day to day working with clients. This is an effective process for sustainability.

### 1.3.3 Limitations with Current Funding Arrangements

#### 1.3.3.1 Inequity of Access

Currently people with acquired brain injury are entitled to different levels of care and support dependent on where they live and how they acquired their disability. People who sustain TBI through motor vehicle accidents are now covered under the NSW LTCS. In NSW people who sustained TBI through other mechanisms e.g. fall, sport, assault, and those with non traumatic injuries e.g. tumour, infection, stroke, aneurysm, do not have the same access. The ‘lottery’ regarding a person’s ability to access adequate lifetime support is a significant issue. People with acquired brain injury will access varying levels of support dependent on how they sustained their injury, the severity of that injury, and where they live. People with injury related disabilities who are covered under third party schemes, including LTCS, access much better support than those who are not covered under an insurance scheme in the current arrangements.

#### 1.3.3.2 Assumptions and Inadequacies of Necessary Infrastructure

Insurance settlements have not always provided the best way of managing life time costs. Often this is because of the limitations in the range of services included not being adequate to meet the complexity of client needs. Insurance schemes have an underlying assumption that services such as housing is available and the required services can be purchased. They usually have minimal or limited ability to promote infrastructure growth or develop sustainable service initiatives by building on existing service networks.

In NSW the Lifetime Care and Support Scheme has a mandate around treatment rehabilitation and care and the structure of a fee for service based on identified goals. The Scheme provides equipment and home modifications but does not include purchase of accommodation for the individual, relying on personal ownership, public housing and private rental. A place to live that is appropriate to the person (and their family) is fundamental need when living with disability especially when life choices have been reduced. Five years following introduction LTCS is now purchasing and building accommodation to solve some of the issues for people who are unable to live with family. People with TBI often have problems living with others (approx 50% across all ages have challenging behaviour after TBI) and have limited options to live alone when care hours are not available 24/7 unless hours are shared by co-location.

### 1.3.4 Opportunities for People with Disabilities: the NDIS and NIIS

The introduction of a National Disability Scheme that brings together insurance and disability will enable a greater proportion of people with disability maximise their health, social inclusion and productivity. To achieve this the National Disability Scheme needs to provide people with disabilities the best that science and engineering can offer by including clear pathways for the involvement of research that takes a collaborative approach into the broader study of healthcare, rehabilitation and independent living (including employment, interpersonal relationships and social networking). There is also an urgent need to build infrastructure and establish an ongoing process to ensure that services are available for people with disabilities at the times they are needed and that there is potential to develop new initiatives and opportunities to improve the social inclusion of people with disability.

# *FEEDBACK REGARDING*

# *PRODUCTIVITY COMMISSION REPORT*

The Productivity has summarised the main recommendations arising from each chapter within their report. Those recommendations where specific issues related to the needs of people with brain injury will be reviewed. There are four main areas this submission addresses. First, the level of service and need to be addressed by the proposed scheme will be reviewed. Second, issues related to eligibility and assessment, including the process, considerations for selecting appropriate objective measures of outcome and actual assessment tools. The issues regarding appropriate assessment was identified as an area where the Productivity Commission sought additional information, and this has been addressed. Third, considerations to support the delivery of services, including interactions with other agencies will be reviewed. Finally issues regarding implementing and maintaining the scheme are reviewed, including workforce, funding and managing the necessary change to get the scheme established.

## 2. Who is the NDIS for?

The opportunity to abolish the 'lottery' of reasonable rehabilitation and care to meet the lifetime needs of people with complex disabilities must be realised. People with non traumatic brain injury will access the NDIS, but dependent on when their injury was sustained those people with traumatic injury will utilise funding through either system. The early onset of injury for most people with TBI means this use of dual systems for people with traumatic brain injury will be long term. **The need for parity between the two schemes is essential if the aim is to remove the current 'lottery' arrangements.**

**Draft Recommendation 3.1. Three main functions of NDIS**

**Aim of support to both minimise impact of disability AND increase a person's participation is commensurate with mission statement of the NSW BIRP. Participation in social and leisure activities, particularly where return to vocational roles is not possible is of particular importance.**

The three tiers described in the Draft report usefully distinguish the roles of the NDIS. Comments regarding the three tiers in relationship to the needs of people with moderate to severe brain injury are provided below.

### 2.1 Tier 1

The NDIS could take led in consultation to increase awareness – build on current and planned work of state health, disability and NGO organisations.

## 2.2 Tier 2: Ensuring Appropriate Support

A single ‘one stop shop’ for referrals and information about care and support options is admirable. This would mean people approaching NDIS would be directed towards appropriate services even where their needs did not meet the eligibility criteria for NDIS funded care (Tier 3).

Services, including the NSW BIRP, are increasingly developing information and training resources to support people, although currently some information or support is often needed to access them. For example. The Next Step provides a manual for information for young people with brain injury as they transition from children services to adult services (See http://www.health.nsw.gov.au/initiatives/birp/birdreports.asp). Other brain injury resources for people with disability and their carers are available at http://www.maa.nsw.gov.au/default.aspx?MenuID=142). Testing of the proposed database (Draft Recommendation 8.1) should be done by people with disability and carers to ensure the resource is truly accessible for those it is designed to assist.

## 2.3 Tier 3: Individually tailored funded supports

The need to target those with the highest support needs is unquestioned. However calculating what level of need warrants such funding is challenging. The issues of how terms such as ‘profound’ and ‘severe’ may lead to inappropriate identification of eligibility have been identified. Clarification regarding definitions for similar terms and how these are applied may address this. A flowchart or decision making matrix may assist in identifying the range of factors to consider. There are likely to be several diagnoses that provide a first level determination of need, followed by reflection of a certain level of supports required (or provided) to address core and non core activities. Issues such as cognitive impairment and behaviour may warrant additional highlighting. It is likely deciding who meets eligibility for Tier 2 or 3 is a difficult one, particularly for people with brain injury whose needs may not be physically apparent on first inspection.

People with brain injury are often overlooked in the provision of generic and disability services. The BIRD has represented NSW Health in an Interagency Working group with ADHC, NSW Health (involving ACI, Justice Health, Mental Health, Drug and Alcohol Office, State-wide Services, Primary Health and Community Partnerships Branch), Department of Housing and LTCS to ensure services are used effectively and people don’t “fall through the gaps”. One of the main outcomes of the ABI interagency agreement was that ABI was recognised as an eligibility criterion, as many people with ABI were not accessing appropriate services. It is noted that the discussion on the specific needs of people with intellectual impairment, “they have difficulty in learning and applying knowledge and in decision making”, and “it is therefore important to also consider the level of support that is needed in non-core activity areas, especially making friendships, maintaining relationships and interacting with others” is equally appropriate to most people with moderate to severe brain injury. The work to develop interagency pathways that support the process have been developed.

A similar process for children, including ADHC, disability, education and health services (e.g. brain injury, child mental health, Department of Education, NDIS and NIIS) could achieve similar pathways to improve access for children and young people with disabilities. A similar approach for NDIS and NIIS may be helpful to ensure people with brain injury do not again lose out.

The prevalence of challenging behaviour after brain injury is high, over 53% adults and 51% children with TBI have significant behavioural problems that impact on their ability to engage with others and manage in the community (Sabaz, 2011). Withdrawal of services is common for this difficult to manage group. Unmet needs are often high and were found to include: family education, drug and alcohol services, behaviour management, disability services, education assistance, vocational assistance, counselling and living skills training (Sabaz, 2011). These people are often unable to identify their own needs, and carers of people with challenging behaviour may have little opportunity to advocate for the loved one due to the high demands involved.

While people with TBI will ultimately be managed in the NIIS, whichever scheme someone receives funding from should not impact on the services available, or eligibility for services. ABI has been identified as an early intervention group, but within two years after brain injury the permanence of disability could be reasonably assessed for most people. Criteria needs to be sensitive enough to ensure those at the cusp of needing lifelong versus episodic care (under auspices of early intervention) are captured. Mechanisms and information
Is required so that people who need episodic support under early intervention can easily re-engage with services and paperwork is kept to a minimum e.g. no need to repeat paperwork regarding diagnosis.

#### 2.3.1.1 Targeting Beneficial Early Interventions Via NDIS.

The BIRP model for adults with brain injury has been depicted as a service offering early intervention to people who have recently acquired brain injury. The periodic nature of this requirement, early after injury and as needs change over the longer term, has been acknowledged in the NDIS proposal and fits with the current model of the BIRP. People with rehabilitation needs can be referred any number of times, usually up to the age of 65.

The model of care for children with brain injury in NSW is continuous service from the time of injury until the child reaches the age of 18 years. In practice there is episodic service provision for most children, but services can be accessed at any time, without a new referral required. The impact of childhood brain injury poses particular issues. The impact of the actual injury is ‘superimposed’ upon the normal developmental process. The consequences of brain injury may not be apparent for several years, particularly in young children. Children who sustain their injury under the age of 7 have been found to be particularly vulnerable to longer term impairment and disability (Anderson, Catroppa, Morse, Haritou and Rosenfeld (2005). When children reach the age of 18 they can access adult rehabilitation services whenever rehabilitation needs have been identified.

Early intervention, soon after the onset of disability, but perhaps more so longer term, often includes co-ordinated input from a number of agencies. To maximise outcomes for people with disabilities strengthening interagency pathways to support early intervention and other management is considered beneficial.

## 2.4 Bringing it all Together

The occasional disparity between ‘mild’ level of diagnoses, such as intellectual disability and actual care and support needs has already been identified. This may be the case for someone with mild brain injury, particularly in the presence of co-morbidities. There is a need for a level of functional or care and support needs assessment in addition to any relevant diagnostic criteria. It may be possible, perhaps once early data regarding needs has been accrued, to identify the common ‘combinations of diagnostic and functional criteria to determine eligibility e.g. moderate brain injury and presence of challenging behaviour or dual diagnoses. The design of the NDIS database could accommodate such data queries and analysis.

The NSW BIRP is keen to demonstrate systematic evidence of service outcomes to support service evaluation and improvement. Three projects to identify and evaluate measures of outcome have been completed. These show the measures demonstrate good change in both core and non core activities for adults in BIRP community and transitional living programs. Measures for paediatric services showed early promise but require further investigation before they are introduced into routine practice. The BIRD is aiming to develop a strategic sustained research programme that addresses key clinical priorities which may fit in with the proposed research arm of the NDIS. Opportunities for national research regarding brain injury services and outcomes will be explored as part of this process.

# 3. HOW TO DETERMINE THE PEOPLE MOST IN NEED OF SUPPORT, THE SERVICES THAT SHOULD BE AVAILABLE TO THEM, AND SERVICE DELIVERY ARRANGEMENTS?

This section will address key aspects of determining eligibility and needs via assessment. Issues regarding the process will be highlighted. The BIRP have completed three projects to identify trial and evaluate measures of outcome for routine use. Lessons derived from these projects relevant to the introduction of NDIS will be described.

## 3.1 The Assessment Process

**Draft Recommendation 3.7 An independent forward looking assessment process should determine the level and nature of supports required by an individual**

**This will ensure unmet needs are not perpetuated by the new system. The experience of the BIRP is that referrals or requests to services where there is a low expectation of approval are usually not made, so the real level of demand is hidden.**

Including the person with disabilities as part of the assessment process will enable them to express their own views about their needs, interest and own circumstances. However additional sources of information are essential to ensure objectivity and consistency in decision making. Information will need to be obtained from multiple sources, including objective assessments. During the process further collaboration will include presenting assessment results in a meaningful way, and discussing interpretation and implications of results of more objective and external assessments, including information from services and results of measures of outcome and need.

Objective assessment tools are designed to determine, for example, a person’s care and support needs or level of disability. Applying reasonable and necessary, or other criterion, is beyond the capacity of existing tools, and is a second or subsequent process.

### 3.1.1 Assessing Needs for care and Support

**Draft Recommendation 4.1**

- **The NDIS should cover the full range of supports considered reasonable and necessary.**
- **The NDIS should support the development of innovative support measures.**

**How will 'full range" of disability supports be determined? Services considered valuable by people with brain injury and their carers, plus brain injury rehabilitation clinicians, are often not approved. In NSW the LTCSA has made interpretations regarding what constitutes lifetime care and this is considered quite narrow by many clinicians. Currently 100% of what clinicians feel are needs arising from injury are not always covered. Additionally where pre-existing disability exists, these needs are not covered by the current arrangements which lose the whole person approach to rehabilitation and care.**

- Current service provision at the time of assessment may under-represent real need. However people with brain injury with severe cognitive and/or behavioural problems who may not be realistic about their needs and report less needs when assessment relies on the person with disability.

### 3.1.2 Assessing Informal Care

Determining what level of informal care is appropriate should also consider what is sustainable. Many carers operate under extreme stress and burden, and whilst they may have managed for many years, this may be due to lack of acceptable or available alternatives. Informal care arrangements, particularly where funding is provided for this, needs to ensure the arrangements are the most appropriate to meet the needs of the person with disabilities, whilst still considering the context in which they live.

### 3.1.3 Eligibility criteria

**Draft Recommendation 3.2 Eligibility criteria**

**It is interesting that people with intellectual impairment have been identified as a distinct group for the NDIS, partially as they may require significant support to participate in the community, but lack specific disabilities regards mobility, self care or communication. This is equally true of people with acquired brain injury. ADHC introduced ABI as a diagnostic criteria for service eligibility in 2008 (Stronger Together 1). This occurred due to inequity of access for people with brain injury who didn't meet low IQ criteria, but who may not always fit in with rigid groups such as physical disability. One suggestion is that a criteria regarding cognitive capacity to function independently in the community may assist – this could be supported by neuropsychological assessment data, and evidence on the extent of impact on their social and community participation.**

The initial severity of the brain injury influences short and long term outcomes: the more severe the injury the greater the likelihood of lifelong disability [Australian Institute of Health and Welfare, 2007; Wood, and Rutterford, 2006]. Most people sustain mild brain injuries, and make near or full recovery [Australian Institute of Health and Welfare 2007, Access Economics, 2009; Koch, Narayan, R.K., Timmons, D.

(2010]. About 10% sustain severe brain injury, and this group “accounts for a disproportionately greater degree of the mortality, morbidity, and [associated] costs of care” [Gray, D.B., and Hendershott, G.E. (2000). As the incidence of brain injury peaks in young adulthood, survivors generally have decades of reduced quality of life and the burden and costs associated with long term disability [Access Economics, 2009]. Children are more vulnerable to the effects of brain injury. Young children in particular experienced greater disability related to the severity of the injury than older children or adults, with pervasive developmental problems experienced over the lifespan (Anderson, Catroppa, Morse, Haritou, Rosenfeld**,** 2005).

As with many people with intellectual impairment, “people with ABI do not necessarily have higher support needs in the core activities of daily living, or require a greater intensity of assistance with these activities. However, they may have more complex or diverse needs for support and assistance, particularly in life areas related to independent living” (AIHW, 2007). Criteria that focus only on core activities will create gaps in and people with brain injury with complex needs and disabilities could miss out on adequate services.

People with brain injury may not have clear disability with core activities, but the presence of challenging behaviour may involve considerable supervision and support needs. Challenging behaviour can include lack of initiation, verbal and physical aggression, and inappropriate social behaviour. This can be disruptive and put the person with brain injury, their carers or the community at risk of harm. The risk of challenging behaviour generally increases with injury severity, but people with mild and no disability can still experience challenging behaviour (that commenced after their brain injury). Whether this group of people will meet the criteria needs further debate, but additional services are required above current resources (See http://www.health.nsw.gov.au/initiatives/birp/birdreports.asp for further information).

#### 3.1.3.1 People with Disability Related to Chronic Conditions

There are specific issues regarding people with chronic health conditions. First, people with brain injury are more likely to experience chronic health conditions and poor health (AIHW, 2007). This is likely to be true of other health conditions, thus NDIS needs to develop clear pathways between health and disability services to meet these needs. Second, eligibility for NDIs funding should primarily be based on need – whether disability in regards to needs for care and support arises from illness, congenital or acquired conditions should not prevent people with illness related disability from receiving appropriate support. It is likely that these people will need greater coordination with the health system to ensure their health and care needs are met.

### 3.1.4 Assessment regarding Eligibility

Assessments need to target the main issues that support eligibility to the scheme. This would currently include:

- Extent of communication, mobility and self are related disability
- Intellectual impairment – evidence from specialist (required once to support eligibility – not re-requested at following stages
- Early Intervention – this will need clarification as all people with any level of disability would hope early support is available. Guidelines for specific diagnoses may be helpful (but should not be exclusive). This could include strengthening interagency pathways to help prevent decline e.g. better integration and support within education, better opportunities for resuming/

accessing the workforce (research suggests unemployment id disabling condition in it's own right).

- Large identifiable benefits from support
  - Brain injury is often a small group with long term high care and support needs. These do not always fit within basic communication, mobility or self care. Aspects that may warrant additional criteria include:
  - Challenging behaviour – or at risk of challenging behaviour
  - Have disability and live in rural or remote location – additional transport
  - Have disability, and accommodation costs may be needed
- Assessment of appropriate Tier of funding – would need to consider timeframe of disability, extent of needs, degree to which local services meet these needs? An issue for people in Tier Two is that current services are often provided in silo's and have rigid admission criteria or restricted length of service – the risk being people with moderate or severe disability may not in fact receive appropriate long term support from these agencies. The need for multiple agencies to meet a person's need may warrant eligibility to Tier 3, at least until local services improved – this would need to be explored further.

### 3.1.5 Regular Reassessment

Natural transition points often are difficult to monitor e.g. loss of support, getting a job – system needs to accommodate this (e.g. in addition to regular scheduled assessments such as every year or two). Regular re-assessment could be scheduled according to timeframes, but a process to trigger reassessment when needs change unexpectedly is also required. Regular communication about the availability of reassessment will ensure people don't wait until reassessment is offered. Communication could be via letter, email, website. SMS or phone. In remote areas, where electronic communication is limited, this information may need to be conveyed through local services, e.g. Aboriginal Health Centres. Reassessment could include phone calls regarding whether needs have changed before a full reassessment process is triggered.

### 3.1.6 Measuring Outcome and Evidence of Effectiveness

The Productivity Commission highlights the need to collect systematic data on outcomes and inputs. Measuring outcome requires change in scores on objective measures to be calculated. Measures regarding participation would need to be done early on, and could be used to provide additional evidence of a person's complex needs, in addition to basic assessment regarding core activities of mobility, self care and communication. A challenge for NDIS and NIIS is to identify measures that enable assessment of functioning and need that are sensitive to people with a variety of health conditions. In discussion with clinicians, LTCS and the Australasian Rehabilitation Outcomes Centre (AROC), the BIRP advocate that generic measures are often unable to detect meaningful changes or needs of people with brain injury, and that more than one measure may be needed. The timing of these assessments does not need to be the same. Disease specific measure could be validated for people with other conditions, which makes sense for measures targeting participation (e.g. University of Sydney Rehabilitation Studies Unit is currently validating a measure designed to measure changes in participation after traumatic brain injury for people with spinal injury).

Multidisciplinary rehabilitation is effective at minimising the impact of brain injury [Cullen, Chundamala, Bayley, and Jutai, 2007; Turner-Stokes, Disler, Nair, and Wade, 2005; Malec, 2009). However 'a dearth of programmatic research has been a clear limitation in advancing rehabilitation treatment in TBI (Whyte, 2009). Rehabilitation research needs to be strategic and sustained and should be seen as a developmental process that would enable services to develop evidence regarding the effectiveness of intervention and service models (Whyte, 2009). The need for systematic robust research has been recognised in Australia (Commonwealth of Australia, 2011). Not funding intervention that lacks evidence may mean services are not provided even when there is not high level evidence available. Randomised controlled trials are not commonly employed in brain injury and take long periods of time to complete with brain injury. Identifying evidence that exists, the level of evidence and areas where evidence is lacking would support identification of research priorities. E.g. MAA project regarding management of mild TBI guidelines developed utilising best available evidence plus consensus where evidence lacking. Evidence of individual progression and benefit from services can also be obtained using individual measures including measures of outcome, client and carer feedback and goal achievement.

The BIRD is in the process of applying for an ARC scholarship to develop strategic program of research in the field on brain injury. This process could be used by other services/ agencies.

## 3.2 Considerations in Selecting Suitable Assessments

### 3.2.1 Criteria for Selection of Measures of outcome and Assessment

The selection of objective measures will be difficult due to the wide variety of needs and diagnoses potential participants in the scheme will need considered. Increasingly test developers and authors are advocating the aspects of measures that should be considered. As a starting point test developers agree assessments need to be both clinically useful and psychometrically robust to be used in clinical practice (Streiner and Norman, 2003, p.9; Smart, 2006; Andresen, 2000; Tate, 2010; Polgar and Barlow, 2005; Hobart, Lamping and Thompson, 1996). To evaluate these factors requires evaluation of a tool's reliability, validity and sensitivity to measure change as well as practical considerations such as time, cost, burden and acceptability to clinicians (Andresen, 2000; Wade, 2003a; 2003b; Smart, 2006; Polgar and Barlow, 2005; Unsworth, 2000; Hall, 1992).

Increasingly the relevance of the purpose of the test needs to guide evaluation on whether the assessment is useful for any given purpose. In this way, assessments of eligibility for the scheme may need to be different from assessments to measure a person's progress. Given the implications of assessment – the opportunity to access significant person centred funding – it is imperative that objective measures have robust measurement properties. This is likely to be lacking in most cases but will need to be addressed as a matter of urgency once the scheme is established. Generic measures may not address the essential issues, or lack validation with people with a variety of health conditions. Measures of participation may identify need, and could address both the key aspects of communication, mobility and self care, and also the range of other aspects identified in the draft report (accessing the community, managing money). There are several resources that can provide some criteria for selection of specific tests, and also broader considerations (dignity and respect, enabling individual choice) (COAG, 2011; Commonwealth of Australia, 2010).

The ICF provides a useful basis for identifying the key elements of participation that should be considered during the assessment process for people with complex disabilities (Cieza and Stucki, 2005). The extensive nature of the classification makes it difficult to apply in clinical practice and this has limited its widespread use in routine clinical practice to date (McIntyre and Tempest, 2007). Several approaches to using the ICF to develop condition specific tools have been developed, but they either lack relevance for people with brain injury or other specific conditions (Bernabeu, Laxe, Lopez, Stucki, Ward, Barnes, Kostanjsek, Reed, Tate, Whyte, Zasler, Cieza, 2009; Sherwin, Whiteneck, Corrigan, Bedell, Brown, Abreu, Depompei, Gordon, Kreutzer, 2006; Koskinen, Hokkinen, Sarajuuri, and Alaranta, 2007). Koskinen, Hokkinen, Sarajuuri, and Alaranta (2007) found the ICF Checklist was inadequate for documenting the impact of brain injury due to its restricted scope, the diverse nature of brain injury related disability and limited reliability of the qualifiers. However the use of ICF domains and items to 'match' assessments, particularly where discipline specific Assessment tools are used, may be an approach to ensure consistency in how eligibility is determined for people with different conditions. At a later stage, 'scores' on different tests could be compared.

## 3.3 Assessment Tools

The BIRD has introduced a range of criteria to guide the selection of assessments including:

- Acceptable to clinicians
- Realistic given time constraints and pressure on services and clinicians – doesn't take too long to complete
- Reflect issues addressed during clinical practice (not merely tools designed for research). BIRP clinicians identified key issues relevant for rehabilitation for adults and children after brain injury that were used as criterion to identify appropriate assessments
- Fit for purpose: able to detect changes in clinically relevant issues to demonstrate how people change over the course of a rehabilitation programme
- Adequate measurement properties: reliability, validity, sensitivity to measure change (for outcome measures)

These were developed based on a review of the literature and clinician consultation. The people who are to use the assessment tools can provide valuable information on their clinical utility (time taken, acceptability, burden on respondents, and clinical meaningfulness of information). This is important information when planning change management required introducing changes to clinical practice.

The BIRD have completed three projects to identify and evaluate a number of objective outcome measures for use in the eight Transitional Living Programmes (TLPs) and community based services for adults and children. Based on the results of these projects the measures in routine use include:

- TLP: MayoPortland Adaptability inventory (MPAI) and Functional Autonomy Measurement Scale –TBI version (SMAF).
- Community (Adults: MayoPortland Adaptability Inventory)
- Community (Paeds): No measure in routine use; two measures were piloted including Child and Adolescent Scale of Participation (CASP; Bedell, 2008) and Family Burden of Injury Interview (FBII) – but psychometric issues reported with both measures- plans to address these are being consider by BIRP services.

Experience from these projects has identified following issues that may be relevant to introduction of assessment tools for NDIS:

- Clinicians require flexible training to be delivered in range of options including face to face, workshop style sessions, online and have some access to support. Identifying champions within services has been helpful to implement change. Training has been reported as beneficial by clinicians in absence of recommendations for training by test developers. Clinicians who have used assessment tools in the past have also reported training addressed scoring errors that they had been systematically making.

- Reliability of administration is enhanced when clinicians understand basic principles of objective and standardised tools e.g. concepts of reliability and validity, the importance of following standardised guidelines for administration and scoring, purpose and limitations of assessments.
- There are very few appropriate tools for children and young people, particularly with brain injury. Some generic childhood tools are not considered helpful with children with brain injury (e.g. ABAS-2) and most have not been validated with children with brain injury, or many other conditions. Criteria regarding the relevance and utility of tools need to guide selection of tools when the psychometric properties of tools have not been adequately determined.
- Resources support implementation: training and administration manual and resources e.g. score forms and manuals as relevant. Changes to databases supports collection of outcome data e.g. single point of data entry to meet internal and external data requirements. The BIRD Clinical Data Set can be modified to incorporate new assessment information e.g. LTCS / NDIS assessment tool and other information regarding participants.

### 3.3.1 Assessment Tools Proposed in Draft Report

Six tools have been identified as potentially being appropriate. The BIRD has identified significant concerns regarding the psychometric properties, ethics, relevance, appropriateness and acceptability of the I-CANS (See Appendix 1). Considerable further work is needed on this tool to address these issues, including removal of items on ethical grounds.

Tate (2010) describes several scales addressing support / environment needs: CANS, CHIEF, HACE, ISEL, LSNS, MQE, NPCNA, SSS, SRS, SUNSU. A brief description of some of these tools is provided.

Care and Needs Scale (CANS) (Tate, 2010)

- quick, up to 15 minutes if done via interview
- 24 items
- aim to document support needs
- psychometric properties well established ‘
- based on ICF
- free

Survey of Unmet Needs (SUNSU) (Tate, 2010)

- 27 items
- Person with BI indicates what services they receive and where they have self identified unmet need has been identified (tick for yes, leave blank for no service or need)
- scaling system not reported but can produce total score.
- Consumers involved in development
- Initial validation for TBI group
- Language not reliant on jargon
- free

Supervision Rating Scale (SRS) (Boake, 2000)
5 levels including 13 categories of support – based on what person actually receives. Boakes argued perception of what is needed is subjective and can lead to under or over reporting. The SRS could provide objective data on level of support need (rather than clinical opinion) or could use current hours of care and costs versus I-CAN estimates. Would take a minute if you know person or had other information.

It is recommended the elements considered essential for assessment are identified as a precursor to reviewing assessments. This can support expedient shortlisting of assessments for trial or further consideration.

### 3.3.2 Assessment Toolbox

Given the complexity of issues surrounding assessment for eligibility and service provision, and care and support needs for people with a wide variety of conditions living in different parts of Australia, a ‘toolkit’ of assessments is considered to be the only appropriate solution.

Whatever tools are identified, further validation for people with different health conditions will be required. Identification of appropriate ‘diagnosis specific” assessments will assist in validating more generic measures for widespread use for NDIS participants e.g. BIRD uses MPAI for adults, which could be used to ensure other tools are appropriate for people with brain injury. Diagnosis specific tools may also be found to distinguish different levels of support needs. The NSW BIRD proposes that national measures of outcome could be used for these distinct diagnostic groups – and to implement projects to identify appropriate measures for people with different diagnoses, as well as measures that can be used to compare everyone within the scheme. The second are likely to be more generic and should be as brief as possible as these provide information for the scheme, and not necessarily information to support individuals, which may be better captured by diagnosis specific assessment tools, or participation measures that have been validated for different groups.

There is a particular lack of assessments relevant for Aboriginal and Torres Strait Islander people, and those who live in remote communities, especially those who do not live a western style lifestyle or speak English as their first language. There is also a lack of assessments specifically validated for children with brain injury. These special groups will need consideration, as existing tools and those identified for use in the early stages of the NDIS and NIIS may not be valid to identify needs for these groups. The limitations of all tools in the toolkit need to be acknowledged to ensure the assessment process is fair to all.

Managing demands of BIRD decisions regarding appropriate outcome measures with demands for assessments from LTCS, insurers, National Scheme, AROC –there is a need for collaboration to ensure minimal overlap and minimize burden on people with disabilities and service providers.

### 3.3.3 Monitoring Instruments

The need for monitoring assessments acknowledges that people’s needs may change over time, as they age or their personal circumstances change. Again, identification of key issues will describe the purpose of the assessment and guide selection of appropriate instruments. Repeating the baseline assessments would enable change to be measured in functioning or disability symptoms (dependent on purpose if initial assessment used). Again further information will be required to complete an assessment process. Client and carer satisfaction may be additional factors that require assessment.

### 3.3.4 Diligent Use of Tools

The need for consistency is paramount in how both tools are applied and eligibility and reasonable and necessary is applied. There is likely to be a high number of staff employed, from a variety of backgrounds and experience. BIRP clinicians have reported increasing apparent inconsistency in how decisions are made and expectations regarding paperwork as LTCS continues to grow rapidly. Systems to achieve consistency would be valuable for NIIS schemes such as LTCS and when NDIS and NIIS are introduced. The inconsistencies can arise from both inconsistently approach to completing paperwork, but also by staff who make decisions. Systems to deal with error and inconsistency from all angles are required to ensure people with disabilities do not miss out. Changes to paperwork as systems are tested should be done following consultation, and be kept to a minimum.

# 4. DELIVERY OF CARE AND SUPPORT SERVICES TO MEET NEEDS OF PARTICIPANTS

Once eligibility and reasonable and necessary needs have been determined, the NDIS and NIIS will be responsible for meeting these needs. Several issues relevant to the delivery of services have been identified:

- Criteria of reasonable and necessary are consistent with third party, workers compensation and no fault schemes including LTCS. The combination of goals, action plans and costs can usefully provide evidence of these criteria. However, this approach is not broadly evident in the disability sector.
- The number of episodes of therapy for people with brain injury doesn't have a robust evidence base – and this is likely to be the case for other groups as well – given disability is produced by the effect of the person' health condition, their roles, needs and interests and the context in which they live, people are likely to have differing needs for supports, even given the same level of disability e.g. co-morbidity, ageing carers, pre-existing health problem e.g. mental health may be warranted – or those most in need will be penalised by having to pay or do without additional services. Thus 'evidence' may be difficult to demonstrate via research alone, certainly in the early years of the schemes.
- There are many services providing what is known as 'case management'. Different understanding of this role can lead to confusion. The BIRP have clearly defined the nature of rehabilitation case management services as direct case management. The NSW Department of Aging Disability and Home Care have clear guidelines and policies about what is case management for there provided and funded services. However, for people choosing a case management service there is little information about why one service would be better suited than other case management providers. Clarifying what is meant by 'case management' may avoid confusion and improve referrals into different services.
- Respite is problematic for people with brain injury who don't readily fit into the 'intellectual disability' framework of services. Flexibility in how respite is provided is considered critical to long term support of community living arrangements. Asking families how they want respite services to be delivered rather than fitting people into service types is an important change to support individual choice. There also need to be recognition that out of home residential respite in an appropriate environment with skilled staff can be a meaningful experience for the person by providing peer interaction not readily available in everyday life. The BIRP provides very short term accommodation and a system of booked respite on a fee for service basis with a bed day rate which is

acceptable to people with brain injury and their families (only one unit at present, but the model is effective).

## 4.1 SERVICE DELIVERY ARRANGEMENTS: INTERACTIONS WITH OTHER AGENCIES

**Draft Recommendation 3.3 Advice regarding appropriate services**

**The report states people with disabilities can access services such as counselling from community mental health services. This service is often not available without specific mental illness, and may be provided by private psychologist through Medicare referral from their GP. It can be difficult to integrate this within a system of care for an individual. The availability and access to services varies in different areas, particularly in remote areas where there are very limited services. Capacity of local and existing services is an issue that affects all agencies seeking to provide equitable access to care, rehabilitation and support.**

### 4.1.1 Health and Disability Services

The interface between Health and Disability services is an important element in providing services that reduce barriers to social inclusion for people with disabilities. The onset of disability, particularly acquired after birth, usually involves intensive support from health services initially and then transitions to lifelong services provided by the disability sector with various levels of ongoing health service involvement throughout the life of the person.

In the NSW BIRP the involvement of clinicians in promoting social inclusion for people with TBI is of a high intensity after injury and can continue for many years or episodically as the person and their family re-engage with the service for various reasons and often at times of life changes. Linking health services and disability service to meet the needs of the person with newly acquired disability at a level that requires support services is critical to providing the environment and support that maximises recovery, reduces disability and promotes social inclusion. However integrating fee for service arrangements in the disability sector will require additional resources as they have been used to block funding/individual funding grants.

#### 4.1.1.1 Disability and Mental Health Services

**Draft Recommendation 3.4 Memorandum of Understanding with the health, mental health, aged and palliative care systems.**

**An ABI interagency agreement with ADHC, NSW Health (involving ACI, Justice Health, Mental Health, Drug and Alcohol Office, State-wide Services, Primary Health and Community Partnerships Branch), Department of Housing and LTCS was established to improve the experience of people with ABI and their family. The Interagency working party developed a pathways document supported by the interagency partners that assist in understanding the issues and barriers for access and support. Proposals to manage the identified issues are the current focus of steering committee activity. This collaborative approach is a model that**

**can be utilised to convene other interagency activity.**

**The Agency for Clinical Innovation brings together clinicians and consumers from health networks to contribute to and drive improvement in health services. The disability sector in Australia involves national and state based government and non government services as well as private stakeholders.**

**The NDIS could have a role in establishing and supporting similar Interagency developments to benefit people with disability. These examples can operate at both national and state levels to improve institutional relationships to achieve best practice models of support for people with disability and their families, workers and achieve integrated service networks.**

The mental health services often lack capacity or willingness to take on people with dual diagnoses. Needs in this area are either unmet, managed by private services or NGO (e.g. New Horizons Enterprises, See http://www.newhorizons.net.au/services/?var1=Outreach Support&var2=Sydney). Terminology is important, the term disability may be unacceptable to people with either mental illness of brain injury, and consumers may need to be consulted to identify acceptable wording so they access appropriate care and support.

This draft makes a clearer distinction in the overlap between Aged Care and NDIS is clearer in this draft version – co-payment makes sense to maintain equity, as long as the level of care didn't change merely because a person turned a certain age.

### 4.1.2 Vocational Rehabilitation and Support for return to Work

Return to work is an important rehabilitation outcome for people with disability. People with TBI struggle to return to previous employment, change employment goals or develop the skills required to achieve meaningful alternatives. There is a need to interface vocational disability services with a rehabilitation approach and improve access to a range of different return to work options with different levels of support and assistance that may need to last longer than currently available. Currently on average the employment rate is reduced for people with brain injury in Australia by 34.3%.

### 4.1.3 Disability and Education

The BIRD made a submission regarding the needs of children with disabilities in education (See Appendix 2).

### 4.1.4 An Example of Co-ordinated management of Rehabilitation, Care and Research

In the United States the Department of Education, the Office of Special Education and Rehabilitative Services has three components that bring together science and services. The National Institute on Disability and Rehabilitation Research (NIDRR) operates in concert with the Rehabilitation Services Administration and Office of Special Education Programs to bring together the scientific community with institutions. NIDRR research is extra-mural, conducted through a network of projects and centres of excellence. This may provide a framework for developing a similar integrated approach in Australia to bring together different government agencies, manage the identified infrastructure growth, maintain and improve service quality and workforce growth (See http://www.ncddr.org/new/announcements/nidrr_brochure.html).

# 5. Establishing and Maintaining the NDIS and NIIS

## 5.1 WORKFORCE: IMPACT AND IMPLICATIONS

The network of clinicians involved in the NSW Brain Injury Rehabilitation Program has experience with the disability workforce. This occurs when arranging paid carers to support people with new injuries move home for the first time, to move to different housing and supported community living care arrangements (eg shared housing). Over the life of the person clinician involvement can be long term over years or episodic, often at times when paid and unpaid care arrangements change. Integral to this involvement is education and training. This will be specific to each individual client, supporting families to manage the involvement of paid carers that often occurs in the family home and extends to providing education and training to the paid carers and the organisation within which they work about the broader issues for working with people with acquired (traumatic) brain injury and supporting staff who work with people with ABI/TBI.

The recognition provided in the report of the importance for improving the disability workforce capacity is supported. However, it is important when developing new strategies and enhancement of existing services to recognise the importance of having staff available at the time needed who are also the right person for the job available.

Additionally, the need to attract different people into the sector by not making pre admission education and training limitations is supported. The attitude and approach of paid workers to people with disabilities is critical to positive outcomes for the working relationship. Current education can provide a bias that reflects negatively in different situations. For example, aged care training is often about taking over tasks as the person becomes increasingly unable to do for themselves. Therefore, some staff has difficulties with providing support to manage cognitive and behaviour difficulties to enable young adults to take risks and opportunities for achieving independence and personal goals.

However, there are disadvantages to promoting an uninformed workforce if the disability organisations are unable to provide the infrastructure that promotes professional development and supports staff to work with people with disabilities from all types and in a range of different life circumstances. There are significant workforce issues for a range of small and large disability organisations in providing training and support to staff following recruitment. Community services struggle with this aspect of service management. Often managers and supervisors themselves have limited training outside of the agency within which they work and have progressed. Training provided by agencies is often focused more on organisational priorities (eg OH&S issues) than professional development of their workers. Often they do not have the resources or management framework to manage transition of knowledge about individuals across different staff, support staff with on the job training or to access external study opportunities. Professional boundaries are blurred and staff stress is not identified or managed contributing to high staff turnover, particularly when the person needing support has complex care needs.

While the reasons for this are complex, there are some key issues about how disability services are funded and how fee for service rates are determined. Importantly, staff who work with people who have complex issues can exacerbate care needs when they do not understand why and how care is to be provided. This is evident clinically and in the BIRD Challenging Behaviour Project Report (in print) where paid carers were found to be contributing to poor behaviour because they made value judgements and so did not see the need to maintain programs to manage behaviours. Often the result was that the person with cognitive and behaviour changes after TBI was excluded from social activities, the cycle of poor behaviour escalated and they became socially isolated. Improving the knowledge skills and understanding of paid carers through training and support can improve the social inclusion of people with disabilities.

There is a need within the disability sector to improve the links between the agency providing paid carer services and the quality of the paid carer services. Quality is improved when there is sector support for including research into practice, for collaborating to improve existing standards for enhance the options available to people with disabilities. Workforce capacity is only one aspect of this goal.

There are issues with recruitment in rural and remote NSW that are probably evident in other areas of Australia. There are additional issues faced by Aboriginal Peoples when deciding to accept paid carers. In the BIRD Rural and Remote ABI Service Delivery Project (in print) these issues were identified and a number of strategies were recommended to improve access to services and supports. Life was tougher for people returning to these communities after a newly acquired injury.

A key concern of families is not only workforce capacity but workforce quality. Families can often be the person/s the agency relies on to train staff and monitor staff performance although this may not be a role that families seek to participate in and can add to their burden of care. An appropriately trained experienced and available workforce can reduce the burden of care for families, particularly when the person with disability cannot manage the complexity of recruitment, management, training and support of staff independently.

Developing a strong disability workforce requires a commitment to evidence based practice and education by supporting organisations to train and educate their staff to enable them to work better with people with disabilities. Improving access to adult learning styles (eg mentoring, buddy systems), education and training funding (eg trainee courses, scholarships) and paid study leave for courses external to the organisation are strategies for consideration. How to include these in building a stranger disability workforce needs to be an essential component of the NDS. In the United States the Department of Education funds the National Institute on Disability and Rehabilitation Research (NIDRR) to incorporate issues of self help, consumer control and respect for life experiences into the broader study of health care rehabilitation and practical life experience. NIDRR has a unique role in federally funded activities to integrate disability research into policies regarding science and technology, health care and economics. The NDS could benefit from a similar federal funded approach with a grants and scholarship program as part of the initial implantation to improve infrastructure and then potentially as part of the NDIS and NIIS structure to maintain, enhance and grow a quality disability workforce.

## THE COSTS, BENEFITS, FEASIBILITY, AND FUNDING OPTIONS OF ALTERNATIVE SCHEMES

The disability network provides a financial structure of block funding or fee for service funding when insurance is available. Recent initiatives include individual funding and activity based funding models. Often disability organisations have little understanding of how to utilise fee for service arrangements to expand program access or how to manage new initiatives so that they are sustainable. The disability sector needs new approaches and improved service options to increase social inclusion outcomes. The NSW BIRP has operated for about 21 years and over this time they have completed a number of research and service projects that demonstrate benefits to clents but are not recurrently funded or integrated into current practice. The supported employment sector has attempted to purchase viable factories and develop integrated workplaces but without the access to the knowledge required to acieve financial success so failed. The introcudtion of the NDIS/NIIS provides an oppoetunity to grow the sector by supporting nerw initiaitives and implementing evidence based practice into working with people with disability. Utilising grants and funding long term programs until they can be sustained by a fee for service arrangement can have a positive effect on opportunities for meaningful participation and practical life experiences.

Generally insurance funding is a fee for service based upon an agreed cost item for an approved purpose once the individual has been accepted to the insurance scheme. In NSW motor vehicle related injuries and work related injury schemes are the most common. These schemes have limits to what can be approved. An example under Workcover is that costs for leisure activities are unlikely to be approved if this is not a pathway to employment. The Lifetime Care and Support Scheme provides reasonable and necessary treatment, rehabilitation and care so again there are gaps in what can be approved and what will assist the individual with disabilities arising from injury achieve their personal goals. It is important that these gaps are identified and pathways into the NDIS are available so the person living with disability is not disadvantaged by the different scheme priorities and focus.

When establishing an insurance approach to managing the cost of disability it is important to ensure that the range of services costed meet the range of services required. NSW Health is able to review the schedule of fees annually for the insurance schemes operating in NSW. It would be important to have a review process during implementation. Assuming that the existing fee for service schedules are appropriate to lifelong disability may not be the answer as it may lead to a range of legitimate disability services and supports not being costed. The range of services for inclusion in a schedule of fees covers employment, health and function, technology for access and function, independent living and community integration and other areas – family, friends and society. Generally the fee for service is related to direct client costs and does not extend to include indirect costs so an alternative approach or additional cost weight needs to be added to the fee, particularly if the organisation is small, specialised or located in rural and remote areas.

Additionally, in the health and disability sector the cost price has often been set historically, it might be an agreed price or a price that is based on a large number of people having the same service so there are cost efficiencies that lower the cost price (activity based funding). Setting the price for disability relies on a large number of people to gain an average, even if the average is for people with similar needs there may be problems applying the formula to all groups. In NSW the activity based funding model disadvantages people with specialised needs who may be low in numbers (volume) and high in cost. This might be people with high support needs from physical communication cognitive and behaviour change as well as health needs, equipment transport and accommodation costs. The individual package arrangements to support people access and participate in the community amy also disadvantage this group because the amount available was determined as an average cost so works for people who are able to participate in group activities. However, when applied to an individual with higher support needs (eg needs 1:1 to participate in a group activity because of cognitive, behaviour, mental health issues) reduces the hours available with no option to increase the funded package.

The model of funding for the NDIS and NIIS needs to accommodate the full range of support by providing access to the funding required so people with disabilities can perform regular activities at home and in the community with opportunities and support for full inclusion in employment, relationships and independent living.

In NSW there have been issues with the introduction of the LTCS that could potentially be reproduced with the implementation of a new scheme into an unprepared disability sector. Some processes were introduced to manage change eg LTCSA Advisory Council, Implementation Committee involving stakeholders, Legislative Council Review process. These processes can assist implementation of a NDIS and NIIS. However, additional gains would be made if there were interagency approaches and pathways for decision making and sharing responsibility for the success of these initiatives. Memorandums of Agreement between stakeholders may provide a less one sided and more equivalent framework for decision making and sustainability.

- Funding arrangements need to support growth of industry e.g. funding to BIRP supports expansion of BIRP services to meet growing demands.

The Disability Sector needs a funding model that promotes growth. The sector is currently not able to meet demand, waiting lists are not kept and planning can occur in silos. Funding that provides a base of activity regardless short term changes in client numbers and supported by a reinvestment strategy increases sustainability. This is an important factor for in growth and responding to local needs.

In addition, a strategy that supports initiatives and new approaches can be incorporated into service development when funding of additional resources is possible.

## MANAGING CHANGE ASSOCIATED WITH INTRODUCTION OF SCHEME – LESSONS FROM INTRODUCTION OF LTCS

- LTCs fund care and support every 3 months – extensive paperwork required, and doesn’t always match clinical and personal needs of people with disabilities, particularly after acute phases when change is slower to achieve.

Another issue is the bureaucracy regarding these schemes consumes considerable time of the limited resources, which further reduces service delivery for people without compensation. The NDIS and NIIS should consider the burden on clinicians and workers to navigate the systems introduced to support the scheme. Change management support regarding these processes will reduce wasted time and improve efficiency.

The scope of change required will be significant particularly for BIRP which may straddle, LTCS, Workers Compensation, LTCS, NDIS and NIIS. Appropriate change management support for service providers needs to be considered. This requires more than distribution of leaflets and presentations, and more interactive workshop style sessions are more likely to ensure staff feel supported and are able to adequately navigate new systems so people with disabilities have their needs appropriately assessed and met. E.g. Case management model strengthened – clinicians and services will need training

People with disabilities also need adequate information. If all people who meet criteria are eligible – how will application and eligibility process be advertised – so people don’t miss out e.g. can health, disability, NGO’s inform people who may be eligible?; how will this early demand be met – with LTCs processes were developed with increasing number of scheme participants, allowing them to be refined gradually. Eligibility regardless of onset of disability is commendable, but will be more successful if people know the process, how long it might take, and how ‘waiting lists’ for assessment into the scheme are to be managed.

**Draft Recommendation 3.6 Following transition ALL people who meet the criteria should have services funded through NDIS**

**A clear process for how this short term peak demand in accessing assessment and access to NDIS funding should be clarified. Appropriate 'advertising' of the scheme to the Australian public and disability and health organisation would reduce chances of people with significant disabilities not being aware of the scheme.**

**The capacity of services may not be sufficient when comprehensive needs are determined for such a large number of potentially eligible people with disabilities. Mechanisms to use initial assessment data to match against available services can inform priorities for service developments (service gaps). This is a particular issues in remote NSW (and presumably other remote locations throughout Australia), where little infrastructure or services is available.**

Funding for services comes with compliance burdens – paperwork changes regularly and is time consuming; lack of consistent feedback makes implementation of change by service providers difficult.

### 5.2 MANAGING POTENTIAL RISKS AND SUGGESTED SAFEGUARDS TO MANAGE RISKS

People with brain injury may have difficulty making decisions regarding care needs and services – e.g. lack of insight, cognitive and behavioural impairment (51% adults, 53% paediatric clients have challenging behaviour). STRATEGY: *People should be assessed as being competent to manage their own affairs before decisions made to enable self management of funds.*

The relationship between Guardianship and NDIS would need to be clarified as some people with brain injury, and other intellectual disabilities, are not able to make informed decisions regarding their wellbeing and finances.

## 6. NATIONAL INJURY INSURANCE SCHEME

This submission has identified a number of issues regarding providing services to people with complex disabilities after brain injury. Although the mechanism of injury and timing of injury will dictate whether people with brain injury are funded through the NDIS or NIIS, the needs and issues will be the same. The issues identified in relation to the NDIs above, are likely to apply equally for the NIIS. The need for parity to ensure equity of access and outcome for all people with disabilities cannot be emphasised too strongly.

### 6.1 Eligibility and Equity for All People with BI Related Significant Disability

The NSW BIRD applauds the inclusion of people with all catastrophic injuries, regardless of mechanism of injury, to be covered under the scheme. People with catastrophic injuries sustained prior to commencement of NIIS will be covered under

NDIS. After NIIS commenced, All traumatic injuries will be death with by NIIS, and non traumatic ABI would be managed by NDIS e.g. tumour, bleed on brain. This will reduce the current inequity for people who sustain brain injuries via motor vehicle accidents and other causes.

Inclusion of all catastrophic injuries, including those for people sustaining injuries through assault and non motor vehicle related accidents would equalise provision of services for people with traumatic brain injury, which currently comprises c.60% adults receiving BIRP services and XX% children receiving BIRP services (add 2009 figures). The remaining proportion of people receiving BIRP services have a non traumatic brain injury and would have their needs assessed through the NDIS. Given clients of BIRP have similar needs, despite different mechanisms of injury, one concern would be whether having NDIS and NIIS would create another source of inequity for people with ABI (including non traumatic and traumatic brain injury).

**Comment [H1]:** Could approximate if you don't have most recent figures to hand

## 6.2 Sustainability

Mechanisms of funding care needs to be sustainable and sufficient in long term, and is beyond expertise of BIRD. However all people with brain injury, not matter how they sustain their injury, or which scheme they are covered under, should receive equitable support where similar levels of need have been identified.

The creation of a national injury insurance scheme is also commendable although retaining state based schemes will perpetuate the different processes, paperwork and requirements of different schemes. This makes it difficult and more time consuming for clinicians to learn and navigate the system. Currently BIRP clinicians are required to complete paperwork for funding for LTCS, TAC, Workers Compensation, and the introduction of Queensland injury scheme and NDIS would add further paperwork.

It is likely that a very large proportion of the BIRP caseload will be eligible, at least for an initial assessment, for the NDIS or NIIS. There are also larger groups of people with other conditions that have provided an initial basis for costing. The ability of the scheme to manage such a large number of applicants, not only for assessment but actual provision of services requires further attention. Realistically, some level of staged introduction may be required – whether this be done on severity of disability, age (children and young people), life expectancy plus or minus other criteria. It is noted LTCS are still developing processes and systems to manage the increasing number of participants, although the scheme has been running for 5 years for children and 4 years for adults, and they currently have only 344 adult and 46 children participants (as of June 2010; Accessed via http://www.lifetimecare.nsw.gov.au/Annual_Reports.aspx).

## 6.3 Development and Evaluation

Utilising existing structures and organisations to guide service level developments will ensure clinicians with experience in disability and health sectors can inform the development process. Clinical networks, such as within the NSW ACI could be used as a model to identify priorities and manage service developments. There has been some discussion regarding whether these could be national, or whether some national forum for state-based networks co-ordinated by the NIIS could be helpful to engage clinicians and consumers. Only a small number would be needed e.g. Brain Injury, Spinal Cord Injury, Burns, Amputations.

### 6.3.1 Service developments

The focus on the inclusion of vocational rehabilitation is applauded. The BIRD is currently working on developing a model to expand brain injury specific vocational rehabilitation services. The difficulty faced by people with brain injury in returning to employment has been highlighted in 4.2.1.3. Issues children with brain injury face have been addressed in Appendix 2. There is also a large group of people with brain injury, who despite the presence of vocational rehabilitation services, will not be able to return to work. Failure to support appropriate avocational (including leisure, recreational and non paid productive activities) activities will increase the social isolation and disability experienced by the most disabled group. This must apply to people in the NDIS, and equity of service provision in this area is essential to meet the aims of the NDIS and NIIS.

# 7. CONCLUSION

The BIRD is excited by the potential for the NDIs and NIIS to improve the lives and outcomes for Australians with disabilities. The BIRD would be willing to provide further input into the scheme, including participation in groups to address the selection of outcome measures and development of the assessment process. The BIRD is expanding its role in research and outcome data collection and is also happy to provide information regarding these aspects of service management.

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# 9. APPENDIX 1

**Review of the Instrument for the Classification of Support Needs (I-CAN)**

## 9.1 PURPOSE of I-CAN ASSESSMENT and REVIEW

The I-CAN is “a support needs assessment designed to assess and guide support delivery for people with a disability including mental illness. It provides a support services and family friendly holistic assessment, conceptually based upon the internationally recognized WHO ICF framework.” I-CAN is a tool largely based on the International Classification of Functioning Disability and Health designed to assess a person’s support needs from a broad range of health and functioning domains. It also aims to support planning and resource allocation. Conceptual basis includes ICF, client centred philosophies and the human rights movement.

The I-CAN assessment has been identified as the forerunner for consideration by the NSW Productivity Commission to support the National Disability Scheme. The purpose of using the I-CAN assessment has not been confirmed e.g. assessment for eligibility, monitoring, structured interview.

## 9.2 DESCRIPTION

I-CAN is a 60 item scale covering an 18 page semi structured interview process. Items are largely drawn from ICF components including Body Functions and Structures, Activity and Participation. Some additional items not drawn directly from the ICF have been added e.g. damage to property and some diagnoses that are coded in ICD-10 are also included in the scale e.g. psychosis, personality disorder, addictions, ADHD. Appendix 1 contains detailed information about the components of the I-CAN but a summary is provided below.

The items are contained in 5 domains:

i. Physical Health,
ii. Emotional and Mental Health,
iii. Behaviour of Concern,
iv. Health and Support Services and
v. Activities and Participation, which has 7 sub-domains including:
    - Applying Knowledge, General Tasks and Demands
    - Communication
    - Self Care and Domestic Life
    - Mobility
    - Interpersonal Interactions and Behaviours
    - Lifelong Learning
    - Community, Social and Civic Life

- The interviewer gathers information about what the person can do, the level of support needed for them to achieve this level and goals. A section to record the need for follow up or goal is also available.
- There are two rating scales applied to items, 6 point scale regarding frequency of support and a 7 point scale regarding the level of support.
- Administration:
    - Time taken: reported to take between 30 minutes - 1.5 hours.
    - Mode of Administration: Interview can be done with individual with support needs but guidelines indicate I-CAN is best done with person, people who

know them best and supports including clinicians, advocates and guardians. There is also a telephone interview script.
  - The administration manual advises several options for rating the I-CAN items are available: ratings the persons own care needs, including variations in care needs for episodic conditions, support needs in different settings, current and future support needs or the difference in support required versus support received.

## 9.3 SCALE DEVELOPMENT

The process for developing and early testing of the I-CAN was described in the manual and Llewellyn, Parmenter, Chan, Riches and Hindmarsh (2005). The validation sample and testing was completed by:

- 16 services involved who provide services in residential and day programs.
- Data collected from 1012 people Male = 58%, Age range 17-77, mean = 41)
- 84% of the sample had intellectual disability as primary disability diagnosis
- 63% from residential care services where 6 or more people live.
- Feedback re utility of the scale for this sample was collected during validation and amendments made.

## 9.4 PSYCHOMETRIC PROPERTIES OF SCALE

The manual provides a summary of studies – more than the website, but the results suggest significant problems with the I-CAN. There are methodological issues in what scales they chose to compare with. Also validation was largely done with people living in residential care, so on this basis not comparable to our client group.

### 9.4.1 Reliability

There is limited information available regarding validation sample. Validation sample limited to largely people with profound intellectual disability living in residential care. For this sample and setting:

- Test retest reliability
  - Results were low or not significant for the Physical health and Mental Health scales (0.22 – 0.55) but this was tested over 1-2 years
  - Result for Behaviour scale was .66 -.7 at one year and .25-.32 at 2 years. This may be OK for intellectually impaired adults but in brain injury we'd expect larger changes – test retest would need to be done in much shorter timeframe (even for people 2 years post injury).
  - Test- Retest results for Activities and Participation were significant (.46 - .93)
- Inter-rater reliability study – unclear re process including how many raters. Results reported = 0.96 – 1.0 (N = 3228)
- I-CAN was correlated with the ICAP, a maladaptive behaviour scale to determine support needs in people with profound ID. Correlation between I-CAN Health and Wellbeing and I-CAN Activities and Participation subscales and ICAP Service level scores ranged from .08 - .69. Sixty percent of correlations were significant. This represents a fair degree of the subscales have very low or not significant correlation with a scale that is assumed to be commensurate in purpose or construct. This data is difficult to interpret without understanding and information about the purpose and properties of the ICAP.

#### 9.4.2 Validity:

There is also limited information about the validity of the scale. Some statistics are reported regarding the relationship between:

- Information to support validity of this scale for this client sample include: I-CAN and ICAP and I-CAN and QOL-Q ( Uncertain regarding aim and properties of this scale)
- Ability of I-CAN results to predict:
  - CSCL, AKGT and Communication explained only 40% variance, other figures not reported.
  - I-CAN only accounted for 23% of support categories detailed by American Association on Intellectual and Developmental Disability.
  - In another study I-CAN domains predicted 58% of staff support hours over a 24 hour period
  - clinician perceptions re amount of support provided (subjective)
- Looked at pattern of scores versus diagnostic groups and living situation (not many results reported).
- There is no information about reliability or validity for people with other primary diagnoses, eg. brain injury (N=20 in sample), primary mental health problems (rather than in combination with intellectual impairment), spinal injury, burns or other groups.

#### 9.4.3 Responsiveness to Measure Change

I haven't reviewed this aspect as yet, only relevant if the I-CAN is to be used to measure change. The need for assessment and purpose for which I-Can is being considered needs to be clear to support robust study design to evaluate its suitability for the purpose.

## 9.5 POSITIVE FEATURES

- Client focused: inclusion of person as lead in describing their own care needs
- Information re the person's interest and goals provides a context for the persons needs to be understood and care to be provided.
- Nice reports generated from website
- Could be linked to client focused goal setting
- ICF linked – fits in with other data sources e.g. ABS etc.
- Motivational nature of i-can philosophy

## 9.6 ISSUES

- I-CAN is essentially an unvalidated tool with promising aspects.
- Managing demands of COP decisions with demands for assessments from LTCS, insurers, National Scheme, AROC – need for collaboration to ensure minimal overlap and minimize burden on people with disabilities and service providers.

#### 9.6.1 Conceptual

##### 9.6.1.1 Overall

- Each section can be rated as not applicable – but ICF includes elements basic to health and wellbeing – optional?
- Confidentiality is overruled when people disclose
- Jargon in rating scale e.g. pervasive level of support, not well understood in brain injury or other sectors. ICF jargon e.g. "digestive, metabolic and endocrine functions"

- Conceptually concerned re measuring support needs for body functions where this should be captured in participation. This seems to be capturing medical and nursing supports but not other aspects e.g. Supervision for self harm, memory etc which overlap in other areas
- In the ICF model of disability and functioning participation in activities and life situations are vital to experience of health and wellbeing, but on the I-CAN Activities and Participation subscales not included under Health and Wellbeing.

#### 9.6.1.2 Tool Specific

- Inclusion of diagnoses in care needs items is inappropriate
- Relevance to people with brain injury and other diagnoses 9 not intellectual disabilities)
- Diagnosis codes limited – have only Acquired Brain Injury (ABI)
- Health Services are included under wellbeing but these are environmental supports not aspects of a persons health
- Obesity scored under physical health, eating scored under mental health, feeding scored under Eating and drinking
- Mental health items confuse diagnoses and behaviours.
- Health and Support Services – do people with sever cognitive or intellectual disabilities really able to identify appropriate services from this list -0 could be adjunct to I-CAN rather than part of interview. House Manager / team leader is not so relevant to BI. Case manager needs to be broken down – rehab / LTCS etc.
- Activities and Participation
    - Lifelong Learning – not from ICF but appears to be service driven from intellectual disabilities – these are a mixture of participation items (work, study, recreation) and service types (business service, day program). Also the items for this will compare people in open employment versus recreation versus day program?? Day program is not a service generally available to people with brain injury.
    - Stress and Safety have items unrelated to each other – handling stress versus water safety. Also Risk of abuse is a judgment – not often made by people who are at risk of abuse – this should relate to support needs for safety due to issues with judgment, insight, problem solving which make them vulnerable.
    - Care needs for Physical and Mental Health will overlap with care needs for Participation as they are not distinct categories .ICF model dictates disability produced through interaction of person, their impairments, environment in which they live and activities they need or want to perform…
    - We would consider people in a day program unemployed.
    - I can .. attend a day programme – how helpful is this as this is a support service
    - Several important omissions: Shopping (household, goods and services), caring for others (parenting), acquiring a place to live
    - Section for self care and domestic tasks may be too narrow given care needs of our clients who may have multiple needs for each area, especially home cleaning, care and maintenance.

#### 9.6.1.3 Clinical Utility

- Time to administer, score and interpret and communicate with client.
- Acceptability – clinicians won’t be happy to have another Ax, will need to address cultural issues re clinician as ‘boss’ (no matter what our mission statement says, goal bank tells it like it is). Considering currently in BIRP clinicians have difficulty completing assessments and goals and LTCS paperwork.

#### 9.6.1.4 Administration

- The administration time is long – up to 1.5 hours. It is expected it would take a long time for people with brain injury in particular. May take much longer for lower functioning clients,  frequency of Ax will impact on what is acceptable
- Concern that consensus regarding care needs cannot always be achieved with people with brain injury and their carers – people in PTA, lacking insight, challenging behaviour etc.
- Insight issues: difficulty to have client centred goals etc when clients lack insight – need to discuss option re X will be important FOR Bob, rather than Bob thinks X is important and how this process is managed in i-can assessment.

#### 9.6.1.5 Rating Scale and Scoring

- Rating for level of support – Managed care needs includes low cost services e.g. meals on wheels – but this is a service to meet care needs for person to have meals – downplays extent of need by linking this to cost.
- Rating scale re level of support relates to cost more than need eg. .low cost service is managed care, services provided to more than 5 people is minor care – even if an individual has high need e.g. cook meals, clean accommodation.
- Rating only most frequent or intense service may under-represent extent of support needs.

#### 9.6.1.6 Psychometric Properties

- The I-CAN has been validated on sample where majority had intellectual impairment and lived in residential care. The reliability and validity of the I-CAN for people with brain injury, spinal cord injury and amputations and other diagnoses has not been established.
- Multiple rating options not validated
- very small sample to evaluate inter-rater reliability
- internal consistency good using traditional stats – Rasch better to support development of new tool
- high correlation with subjective process to categorise clients level of functioning – what about comparison to other measures e.g. CANS, Northwick Park Dependency Scale, GAS
- Characteristics of validation samples would be good to know e.g. diagnosis, age etc.
- Reliability of change scores?? Idea of tracking change is great but need to be sure its valid.
- Cut off scores??
- Does cost calculator relate to costs for private care providers or just government services?
- How is need for and costs for rehab staff decided?

#### 9.6.1.7 Information obtained

- “output’ from web- based programme of uncertain value – costs calculated dependent on agreed costs - ? control over costs as private service vary in their fees. Mix of private and p8ublic services with varying fees.
- Costs relate to information obtained during an interview process.

#### 9.6.1.8 Ethical Consideration

- Ethical considerations and security of data sent to remote database
- Confidentiality is limited according to disclosure
- Consent issues

- Burden on consumers and clinicians – given other requirements for assessment e.g. FIM, AROC (Lawtons IADL Scale), MPAI, etc. Need to balance burden with benefit of output.

#### 9.6.1.9 Cost of I-CAN

- Cost for training and per assessment, plus cost of time for each person participating in interview – if advocates, clinicians etc involved plus facilitator.
- Expensive ongoing costs given tool not validate for our populations
- Who covers cost of training?
- Ready access to internet and computers required
- Software compatibility issues?

**DETAILS RE ISSUES WITH I-CAN**

- I-CAN is essentially an unvalidated tool with promising aspects.

## 9.7 RECOMMENDATIONS / SUGGESTIONS

### 9.7.1 Conceptual issues need to be discussed and addressed:

a. Remove diagnoses from care needs section
b. Consider separate risk assessment to include issues re eating, damaging property, sexual abuse etc
c. Confidentiality is limited to extent of disclosure – mandatory reporting overrides confidentiality
d. Need to review whether additional items required to reflect needs of people with other diagnoses, e.g. parenting, shopping etc if I-Can is to discriminate. Could use activities commonly funded by LTCS as an indicator of gaps.

### 9.7.2 Purpose of using the I-CAN needs to be confirmed – is it the most appropriate tool? What other tools should be considered.

### 9.7.3 Clinical utility: feasibility of administering tool with these groups – feedback from administrators and people with support needs.

### 9.7.4 Establish psychometric properties. Need to ensure tool has been properly evaluated for use in our population and given current demands on services i.e. is it manageable?

- reliability and validity with people from a broad range of diagnostic groups. BIRP interested in TBI, ABI. LTCS also interested in people with spinal injuries, amputations and burns
- Compare to other measures (MPAI / SPRS / SMAF / OBS?) – will need to look at i-can in more detail to decide best way forwards
- Evaluate test- retest reliability with larger sample
- Does i-cans discriminate needs of people with BI versus other diagnoses e.g. learning disabilities need for test retest reliability
- Rasch analysis of tool properties would be valuable to evaluate reliability of the whole tool, individual items and the rating scale and could readily be done on any sample
- Sensitivity to measure change – can compare to other measures now we have good NSW data
- Clinician opinions regarding clinical utility will help with implementation
- ?? seek opinions from our clients/ carers and/ or ACI consumer rep group

- Is it possible to incorporate additional items into i-cans rather than use i-cans and other measures and other goals setting approaches?? Need to know relationships between measures and whether i-cans is sensitive enough to measure change in BI population before this is a serious question – but we could end up expecting too much assessment from an already overstretched service if everything is required.
- Given need to complete FIM – what is relationship between FIM and I-CAN items?

**Table 1: Possible Strategies to Address Psychometric Requirements**

| **Research Question** | **Information Required** | **Suggested Strategy to obtain information** |
|---|---|---|
| Is the I-CAN a valid tool | CONSTRUCT VALIDITY | |
| | Internal consistency | Cronbach's alpha<br>Rasch analysis |
| | Factor analysis | Subscale properties |
| | Convergent / divergent | Higher correlation with similar constructs, lower correlation with dissimilar tools. Need to identify appropriate tools for comparison |
| | Construct: comparison to other tools 'gold standard' re support needs | May need several tools as I-CAN is multidimensional e.g. SF36, MPAI, SPRS, CANS, OBS |
| | Rating scale analysis | Rasch analysis – Rating scale is complex and untested |
| | Concurrent | Comparing results for person answers, group answers and clinician answers |
| Is the I-CAN a reliable tool | Inter-rater | Two raters complete ratings based on interview (N=?). Will need to be done for different groups – inter-rater reliability often worse for BI assessments. Especially important given broad nature of domains – reliant on information obtained |
| | Test re-test | Repeat i-can within 1-2 weeks (identify sample size required) |
| Is the I-CAN sensitive to measure change? | Responsiveness | Compare ratings at 12 months? May need to compare different diagnostic groups |
| Can i-cans predict; what? Previous study used non-standardised clinician perceptions | | |
| Clinical utility | Time taken (different diagnostic groups) | |
| | Acceptability to clinicians / co-ordinators / workers / clients / families | |

## 9.8 REFERENCES / ADDITIONAL READING

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    - Supports, Empowerment and Self-Direction: The Emerging Paradigm in Disability Sector Article written by Sam Arnold and Vivienne Riches published in InPsych that discusses the current movements in the disability sector, including references to a support needs approach to classification and assessment and the I-CAN assessment tool.
    - I-CAN eJHI Article 2009 -CAN general article published in the Electronic Journal of Health Informatics. Winner of Best Peer-Reviewed Scientific Article at the Health Informatics Society Australia (HISA) 2009 Conference.
    - I-CAN Workshop at ASSID Hobart 2009 I-CAN workshop given at the 44th ASSID Conference in Hobart, 4-6th November 2009. PDF version of powerpoint presentation.
    - I-CAN presentation at IASSID Asia Pacific Regional Congress, Singapore, 2009 Presentation regarding our predictive validity study given at the IASSID 2nd Asia Pacific Regional Congress, Singapore, 24-27th June 2009.
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# 10. APPENDIX 2

## LEGISLATIVE COUNCIL GENERAL PURPOSE STANDING COMMITTEE NO. 2:

### Response by the NSW Brain Injury Rehabilitation Program regarding
### The provision of education to students with a disability or special needs

We welcome the opportunity to provide feedback to this enquiry regarding issues in managing the special needs of children with brain injury in the education system. This response has collated feedback from the NSW Brain Injury Rehabilitation Programmes (BIRP) at:

- The Children's Hospital at Westmead
- Sydney Children's Hospital at Randwick
- South West Brain Injury Rehabilitation Service (The Kids' Team) at Albury
- New England Brain Injury Rehabilitation Service
- Brain Injury Team at Kaleidoscope, John Hunter Children's Hospital
- The Paediatric Reference Group, an advisory group supporting the work of the NSW Brain Injury Rehabilitation Programme and the Greater Metropolitan Clinical Taskforce (GMCT) Brain Injury Rehabilitation Directorate which comprises the state-wide network for brain injury rehabilitation services within NSW Health. For more information about the network please refer to http://www.health.nsw.gov.au/initiatives/birp/index.asp

NSW BIRP workers value the opportunity to work collaboratively to maximise the outcomes for students with brain injury. Our overall experience is that schools are willing to work with external staff although the model of working in partnership could be strengthened so it is consistent across the state. In compiling this response we have reported the current issues and made recommendations about access to special education for students with disabilities from ABI, interagency collaboration and improving the interface between the NSW BIRP paediatric services and the Department to improve the provision of education for students with acquired brain injury to maximise learning outcomes.

### 1. Background Information regarding Brain Injury (References in Appendix 3)

### 1.1 Prevalence of Brain Injury in Children and Youth in Australia.

The Australian Institute of Health and Welfare (AIHW) published two reports describing the prevalence of childhood disability in 1998 (published in 2004[1]) and 2003 (published in 2007[2]) taken from Australian Bureau of Statistics disability survey data. These figures revealed an increase in the prevalence of brain injury for 0-14 year olds over the time. In 1998 12,700 children had acquired brain injury (ABI) related disability, representing 0.5% of the Australian population, and 3% of all children with disability in

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[1] Taken from from http://www.aihw.gov.au/publications/dis/cda/cda.pdf

[2] Taken from http://www.aihw.gov.au/publications/aus/bulletin55/bulletin55.pdf

Australia. Nearly all of the children in this group with acquired brain injury (90%, N= 11,400 children) were considered to have a severe disability. In 2003 the statistics suggested prevalence was on the increase with a slightly larger proportion of Australians aged 0-14 (0.5 % = 20,100 children) had ABI with disability but only 12,900 of these which represents 64% of the children with brain injury. The 2003 data also included statistics for ABI disability prevalence for 15-24 years old Australians². Prevalence was much higher compared to the younger children at 1.4% of the population which included 38,000 children. A smaller proportion of this age group experienced severe disability at 25% of this group.

Australian Bureau of Statistics data (2009) suggests that 32.5%[3] of the Australian population live in NSW. From this it could be assumed that approximately 6,353 (32.5% of 20,100) children in NSW have a brain injury. Based on the estimated number of children in NSW with a brain injury with brain injury at least 4,066 (64% of 6,353) children aged 0-14 and 9,500 young people aged 14-25 experience severe disability.

Based on the 2003 data us the number of children and young people aged 0 – 24 in NSW with severe disability due to ABI exceeds 10,400. The prevalence of childhood disability due to other conditions is much higher (Figures for 0-14 reported as being: intellectual disability and physical disabilities= 3.7% of the population each, Sensory and speech disabilities at 3.1% and psychiatric disabilities at 1.1%) but a higher proportion of children with brain injury experience severe disability. Both AIHW reports (2004; 2007) also document that people with brain injury of all ages experience several types of disability and usually more than one health condition, indicative of more complex needs. The prevalence of NSW children and youth with brain injury is an estimated 58,100 with 10,400 estimated to experience severe disabilities is a substantial number. Children and youth within this age bracket include those who will start school in the future, are currently at school and students in post school (including TAFE) options. All of these students are likely to have special education needs to achieve learning outcomes and may currently be falling through the supportive pathways and processes due to rigid criteria.

The figures of students with disabilities in NSW sets the scene for this inquiry. In 2002 20,670 FTE students (the actual number of enrolled students may be slightly higher) attended government schools (16,755 in mainstream and 3,915 in special schools) and an additional 9,060 attended non government schools (7,955 in mainstream and 1,105 in special schools)(AIHW, 2004). In 1998 7.1% of students attending school had a disability (all causes). Of children and youth aged 5 – 20 years old (1981–1998; AIHW, 2004¹) 5.7% have disability due to ABI (3.1% severe). From this group school attendance is varied with 3.5% in normal schools, 1.6% in special classes in normal schools and 0.6% in special schools. In a separate report into students with ABI in primary and secondary schools in Australia (Starling, 1994) an estimated 2000 new cases of children with ABI are reported each year.

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[3] Taken from p://www.abs.gov.au/AUSSTATS/abs@.nsf/ProductsbyCatalogue/FBAC8C9AFBC52291CA25765100098272?OpenDocument

Based on analyses of the Australian Bureau of Statistics' (ABS) 2003 Survey of Disability,
Ageing and Carers the AIWH report (2007) reports:

- ABI is common: around 1 in 45 Australians (432,700 people) had ABI with activity
- limitations or participation restrictions due to disability including about 20,000 children aged under 15 years had ABI
- People with ABI tended to have complex disability. They reported more disability groups and more health conditions than the average person with disability.
- More than one in four (26%) people with ABI reported four or more disability groups, compared with one in eighteen (5%) of all people with disability
- Age at onset figures suggest 33% sustain their brain injury aged 14 or under and 34% sustain their brain injury whilst aged 15-24

## 1.2 Impact of Brain Injury on Children and Young People

Children and young people with brain injury usually present with a complex mix of cognitive, physical and psychological problems. The adverse impact of paediatric brain injury on cognitive, motor and psychiatric functioning is well documented (Ewing-Cobbs and Bloom, 1999; Hawley, 2004; Anderson et al, 2006; Bloom et al (2001).Cognitive impairments include reduced general intellectual functioning (though not in all cases), reduced memory, concentration and importantly impaired executive functioning - the ability to organise, plan and monitor behaviour and performance (Glang et al, 2004). Behavioural changes as a consequence of brain injury can include aggression, dis-inhibition, socially inappropriate or oppositional behaviour or apathy, which can be confused as inappropriate student behaviours. In a study on the psychiatric sequelae of brain injury in children over 76% had lifetime psychiatric diagnoses including ADHD, ODD, anxiety disorder and others, with over 60% of these developing after brain injury (Bloom et al, 2001). These behaviours can impact not only on a student's academic achievement but also their ability to function in the classroom including answering questions, study skills, engagement in classroom activities, social skills in and outside class (DiPerna, 2006). It should be noted a student with brain injury may be variable in performance in the classroom, over the course of a day and week and certainly longer term, which makes recognition of ABI issues more challenging in the classroom setting (Glang, et al, 2004).

A further complication of brain injury sustained as children is related to their age at injury and the interruption of the course of normal childhood development. "The child's course of recovery is superimposed on normal developmental processes, thus having a potential impact not only on previously learned skills, but also on the development of future skills" (Glang, et al, 2004). Changes in demands through the lifespan for children, including starting school, transition to high school and the increased demands of exams as they near the end of schooling can highlight or exacerbate previous problems. Social and emotional demands also change over time (Glang et al, 2004). Thus some children injured at a young age may not experience significant problems until they reach high school where increased competence and independence are required.

Children and youth with brain injury are more likely to have adverse outcomes for education, social participation, quality of life and long term economic self sufficiency (Hawley, 2004; Anderson et al, 2006). Although educational outcomes are the focus of this response the longer term impact of paediatric brain injury needs to be reported. After school a reduced number of people with brain injury complete further education and they tend to have a greater proportion of part time and menial or unskilled jobs compared to the general population. Additionally, they are more likely to be unemployed. People who sustain brain injuries as children or youth are also less likely to live independently so the burden on family and the community persists.

In a recent Australian study children who sustain their injuries prior to starting school have been found to have persistent problems at least 5 years post injury which are slower to recover and with poorer cognitive outcomes including ability to learn intellectual skills, attention and language skills which would detrimentally affect school and overall performance (Anderson et al, 2009). Students who sustain their brain injury while in high school also have poor outcomes, although the impact and nature of difficulties may be different to those who sustain their injuries at an earlier age. Sharp et al (2006) reported adolescents with brain injury have significant trouble fitting back in at school, and the success or failure to do so was influenced by “the extent and quality of organisation, communication and support from parents, school teachers and the rehabilitation team. Adolescents who failed to fit in and experienced inadequate support often left school (Sharp et al, 2006). It should be noted that where students who are not recognised by DET as having a disability are unable to access post school option programmes. For those that stay at school changes experienced after brain injury include downgrading of educational and vocational goals, subjects are changed, poorer relationships with peers and reduced participation in extracurricular activities (Stewart-Scott and Douglas, 1998).

Each student's "educational disability" is influenced by the nature of the injury, the student's premorbid abilities and personality, family supports, the school and external environment (Schutz et al, 2008). School related factors that impact on educational outcomes include educational level, nature of classes and classroom structure, perceptions of the student's classroom behaviour and the availability of support can all affect performance in different classrooms and playground (Schutz et al, 2008; Hawley, 2005). A specific understanding of the sequelae of each child's brain injury, including behavioural and cognitive impairments, as well as other factors influencing their performance is essential to design appropriate educational interventions to maximise a student's academic outcomes (Telzrow, 1987). Without adequate understanding of the impact of an individual student's brain injury, teachers may implement routine classroom 'management' strategies (from a discipline perspective) which may reduce the student's behaviour but will fail to improve their classroom participation and educational outcomes.

Research suggests that the learning needs and behaviour of students with TBI are different from students with other diagnoses and require different assessments and interventions (Glang et al, 2004; Telzrow, 1991). Telzrow (1991) recommends assessments need to be clinically useful, include functional observation and be ongoing to meet the unique needs of students with brain injury and support successful educational reintegration intervention. Glang (2004) suggests that "at the very least, awareness of the existence of TBI [ABI] presents the necessary opportunity to gather information and consider brain injury in assessment, program planning and interpretations of outcomes".

Recognising that students with ABI require different intervention strategies to achieve improved educational outcomes is a vital and urgent need and would be consistent with national and state policy changes. Acquired Brain Injury is recognised as a major disability group in the Commonwealth State/Territory Disability Agreement (AIHW 2004). Ageing, Disability and Home Care (ADHC), of the Department of Human Services NSW, included ABI as a separate eligibility criteria for services in 2009. After the recommendations a more detailed response on the issues faced working with students with brain injury has been structured based on the terms of reference provided.

### Structure of Report

A summary of the recommendations and key points based on the experience of staff working within the NSW BIRP is provided below. Many of the recommendations include strategies that are working in some schools but are not consistently available across the state for what may be a number of different factors not readily understood by NSW BIRP staff.

## 2.0 SUMMARY OF RECOMMENDATIONS TO IMPROVE EDUCATIONAL OUTCOMES FOR STUDENTS WITH DISABILITIES

It is vital a review of the system supports ALL students with disabilities, including those with brain injury receive the appropriate support to meet

their needs. The following recommendations address both education and rehabilitation service issues and are made with this aim in mind:
**To achieve this, the primary recommendation in this report is that ABI should be included in the eligibility criteria for Department of Education and Training (See Appendix 1 for current criteria).**

2.1 Recommendations related to DET:

1. Eligibility criterion need to be flexible enough to identify students with learning needs.

2. Including acquired brain injury as a diagnostic criterion would prevent students with brain injury falling in the gaps. It should be recognised that learning needs may only become apparent years after brain injury was sustained and delay or failure to met developmental milestones will present additional challenges.

3. Transparency in decision making is essential needs for all concerned – the school, parents, rehabilitation staff etc. at all stages in the process for:
    a. Why a student is and is not approved as meeting eligibility criterion
    b. How decisions regarding resources allocation are made
    c. How the funding translates into everyday help for their child in the school setting (who is providing the support, how and for how much of the day).

4. Processes to support transparent and consist approach to working with students with brain injury are needed which include those for:
    a. Determining eligibility
    b. Available educational supports within local and regional levels
    c. Reviewing applications to support students return to school with appropriate support in timely manner.
    d. Improve transition planning for school leavers with brain injury by describing the process for early identification of those students needing referral to transition co-ordinators.
    e. Interagency working with education and health services should be included as a routine practice for students with disabilities including brain injury. E.g. include BIRP workers in Individual Education Plan (IEP) planning and review meetings.
    f. Qualifications of Learning Support Officers (LSO) plus boundaries regarding their role; level of training and support they receive
    g. Roles of staff within schools to facilitate open consistent communication e.g. who should be contacted? Regarding student with brain injury, who needs to be involved in meetings etc
    h. Communication and dissemination of information within schools which includes guidelines when relief teachers are involved and for high schools where many teachers are involved.
    i. Support routine collaboration between brain injury rehabilitation professionals and education staff to identify an individual student’s learning needs and develop and monitor

    individually tailored strategies to meet the needs of each student with brain injury receiving rehabilitation.

  Processes need to be agreed and disseminated at both regional and local school level to support management of students with brain jury within individual services and involving interagency working.

5. Education and training should be provided to education staff including teachers, LOS and teachers aides (as appropriate):
    a. Regarding the nature of acquired brain injury and the multi-faceted and complex, long-term needs of students with a brain injury including managing challenging behaviour.
    b. Regarding applying and monitoring impact of specific strategies often used for students with brain injury.
    c. Modifying curriculums to suit needs of individual students with brain injury and other diagnoses.
    d. How to maximise the presence of a LSO/ teachers aide in the classroom (it is unclear if this is already provided).
    e. how to work with therapy services
    f. Identifying individual learning goals when the student is unable to achieve class learning goals.

   Options to provide training need to be explored but could incorporate existing opportunities including Teacher Education Day provided annually by The Children's Hospital Westmead which is open to teachers, LSO s and schools counsellors. An interagency group could explore further options.

6. Ongoing support should be available to teachers, LOS's and teachers aides working with students with disabilities

7. Exploring ability to expand DET services and policies as follows:
    a. Introduce the life skills curriculum in primary schools
    b. Enable flexible attendance models for students e.g. part time enrolment
    c. Flexible curriculum for early or extended access to work experience for students with special needs.
    d. Introduction of a routine standardised assessment such as the Academic Competence and Evaluation Scales (ACES). The ACES provides an objective indication of the teachers perception of a student's learning needs based on classroom performance that are not related to diagnoses or other impairment based tests. Such an assessment should be explored for use by teachers for all students with disabilities. The BIRP can provide feedback and information regarding use of this assessment.

8. Greater capacity (funding) for school counsellors, teachers aides, IM classes, behavioural support and tutorial centres in mainstream schools and special school placements would facilitate all students with disabilities receiving appropriate support to meet their needs and ensure as many students with disabilities could manage in mainstream schools as possible. Budget issues should not be the guiding factor in determining needs and appropriate supports.

9. Routine consideration of alternative strategies to in class supports should be considered and decisions made on each student's needs. Options include teacher training, teacher release, and modified curriculum.

10. Formal consultation regarding services for students with a disability should include specialist health services such as the NSW Brain Injury Rehabilitation Programme, which is a state-wide network of services providing specialist brain injury rehabilitation as part of the Department of Health. This should not replace existing consultation with consumer organisations such as the Brain Injury Association.

### 2.2. Recommendations Related to Interagency Issues

1. An interagency approach that includes NSW Education, ADHC (children services) and specialist acquired brain injury health services would be welcomed to develop a co-ordinated and systematic state-wide approach to meeting the learning and education needs of students with disability from ABI currently excluded or intermittently accessing essential education support. This would replace the ad hoc arrangements currently in operation.

2. Interagency training should be available across education and health services involved with children to improve awareness of resources (within and external to education, improve collaborative working relationships, share understanding of disability, develop collaborative approach to supporting the student, agree common terminology).

3. Awareness of the resources within health and education should be increased and shared. This should include roles, services offered, resources and contact/ access information so staff from each agency understand what is available and how to access support across agencies for individual students.

4. Recommend that DET and neuropsychological clinicians get develop a strategy to look at application and limitation of neuropsychological test results.

5. Individual students' programmes should be guided by qualified education staff with input from rehabilitation staff as appropriate. It is understood that this takes time to complete. Slow to progress students usually have ongoing high level needs.

### 2.3 NSW BIRP Issues

1. Capacity of the NSW Brain Injury Rehabilitation Programme for students with brain injury needs review. In some rural areas no dedicated BIRP paediatric co-ordinator/ case manager position is funded. The burden on staff from the NSW BIRP and NSW DET for each of the recommendations will need consideration. Recommendations that fall within current capacity and those that would need additional resources need to be identified. A business case and rationale for increased capacity would be required for those

recommendations outside current capacity for health and education services.

2. Rehabilitation staff need greater understanding of the curriculum in order to effectively support teachers develop IEP’s. Difficulty identifying individual learning goals when the student is unable to achieve class learning goals.

## 3.0 RESPONSE BASED ON TERMS OF REFERENCE FOR THE INQUIRY:

### 1. Best approach to determine allocation of funding:

i. Please note that “functional capacity” and “disability” are related issues, as they represent the level of both ability and disability within a person.

ii. We understand that there can be wide variation in functional ability based on diagnosis, but consider that both elements may be useful. The Department of Education and Training (DET) criteria already includes a combination of diagnostic and capacity criteria (See Appendix 1, page 12 for a summary), yet students with brain injury repeatedly struggle to meet these rigid criteria despite having significant learning needs. The current impairment based criterion including language, physical disability, intellectual impairment, mental health, deaf/ blind, hearing and visual impairment often fail to appropriately identify students with brain injury as having learning support needs. Brain injury is not included as a separate eligibility criterion which would enable this client group to readily meet criteria when their learning needs are described as for other diagnostic groups e.g. learning disabilities and mental health. Whilst the option to make individual determinations of eligibility on a case by case basis is available this is time consuming, the reasons for decisions are not always transparent and is an inappropriate waste of resources for children receiving specialist brain injury rehabilitation that have clear needs. This places extra burden on rehabilitation staff and also on parents who are already caring for a disabled child within the family to prove something that is obvious to those working and caring for the child. The impact of this is that many children with brain injury don’t get access to the educational support they need to learn including Transition to employment etc. Any review should provide criteria that set clear boundaries for eligibility but are not so rigid as to block access for students with genuine learning support needs.

iii. Despite the complexity of problems for student with ABI in accessing curriculum and support, ABI is not a recognised as disability for funding purposes. The challenge for students with an acquired brain injury is that often their issues and needs blend into the range of similar sequelae seen in other children with different causality. Whilst the impact of brain injury on a student’s functioning and education needs can vary we recommend that eligibility criterion should include Acquired brain injury of moderate to severe range. Children with moderate to severe brain injuries almost always have a complex mix of impairments, disabilities and restrictions in participating in normal activities. Often the combination of effects reduces a student’s ability to learn and engage in education and criteria that is too rigid currently means many students with brain injury struggle to meet eligibility criteria. Current criteria results in many students with brain injury not accessing the services they need to achieve education goals).

iv. The deficits arising from acquired brain injury tend to be life long challenges that exacerbate over time as the cognitive demands of the school setting increase and disability becomes more evident as developmental milestones are compromised. The ability of the student with an ABI to ‘keep up’ with same aged peers if often confounded by changes to the demand for attention, concentration, behaviour and self monitoring of their own participation in social and learning environments. Sometimes this means a student with brain injury may not have clearly identified needs until some time after their brain injury, such as starting high school where demands are greater, but the more severe the brain injury means cognitive, behavioural, social and learning problems are likely to be experienced immediately after injury, and certainly once they return to or start school. Brain Injury is a life long condition and is comparable to a child with autism or Down Syndrome, rather than an isolated incident from which a child may be ‘cured’.

v. The terms Acquired Brain Injury (ABI) and Traumatic Brain Injury (TBI) can be confusing. ABI refers to brain injury or damage that is acquired after birth and includes TBI as well as brain injury caused by anoxia (lack of oxygen to the brain), brain tumours and other neurological conditions. Traumatic brain injury is a more specific group that includes injury caused to the brain as a result of direct trauma or injury, although the exact aetiology of damage may vary. TBI can be caused by motor vehicle accidents, falls, sporting injuries, non accidental injuries (including shaken baby syndrome) and assaults. Both ABI and TBI describe global diagnoses but offer no understanding of the individual impact and specific nature of the injury in the FUNCTIONAL outcome of the student. Diagnostic terminology does not reflect the significant range of outcomes (cognitive, social, behavioural, emotional, physical) that may impact individual students but moderate and sever brain injury will impact on a student in a variety of these areas.

The BIRP clinicians report that overall in NSW there is not a consistent, nor accurate understanding or a sound knowledge base of the nature of acquired brain injury. As a result, the multi-faceted and complex, long-term needs of students with a brain injury are often not met consistently within the public and private education system.

vi. In regards to eligibility criteria the following issues need to be considered in relation to ABI/ TBI:

a. We support a diagnostic criteria to include moderate to severe traumatic brain injury but acknowledge that the functional impact of the TBI would be required to identify the nature and amount of support a student required. The long term nature and developmental challenges for a student with brain injury need acknowledgement. The ability of students with a brain injury to access the curriculum and participate in normal everyday arenas of school, home and the community are diminished where appropriate support is not provided.

b. In some cases the severity of the TBI has not been determined at the time of injury. Measuring injury severity is unclear for children who are under 8 years of age at the time of injury. International work is ongoing to improve measurement of injury severity for the very young. Measurement of Post Traumatic Amnesia (PTA) is the most reliable approach to measuring injury severity and is not routinely carried out by all emergency departments, trauma units etc. When this occurs the functional impact of injuries often signals the need for brain injury rehabilitation at a later stage.

c. The aim of acknowledging Acquired Brain Injury as a specific disability group is to enhance inclusion, access and participation in normal everyday learning arenas.

vii. Limitations in assessment tools need to be acknowledged for students with brain injury.

a. Most assessment tools do not recognise learning profile or difficulties subsequent to TBI.

b. BIRP tried to introduce a standardised objective assessment called the Academic Competence and Evaluation Scales (ACES). The ACES is an objective assessment regarding school functioning and performance including learning, academic skills, interpersonal skills and participation in the classroom. It is an assessment developed by education staff to identify learning needs of students with a range of disabilities. We believe the ACES assessment encourages improved collaboration between education and health staff to support delivery of effective rehabilitation and academic support for these students. However the return rate by teachers was so poor we have largely discontinued using this valuable assessment. See Appendix 2, page 13 for more information about the ACES assessment.

c. Students with brain injury with any scaled score <70 on full scale IQ to be eligible for funding with diagnosed TBI.

d. Need to recognise that adaptive behaviour scores may be more valuable than IQ scores for some children with ABI. Usually the child has been identified as having difficulty coping with the curriculum before referral to school counsellor or health professionals. Consider starting with functional assessment rather than standardised battery of assessments.

e. Concern has been expressed by clinical Neuro-psychologists working in the area of Brain Injury regarding the use of raw scores from testing to determine the support needs of the student in the school environment. Testing scores alone do not give sufficient information about the functional needs of the student– more analysis of function is needed for students with special needs and disabilities. It is generally felt that it is the functional needs of the student should be used to determine the need for support services rather than testing scores that allocate funds on a of students within the school environment or based on diagnostic grouping. It is recommended that the process of using raw scores to determine support be reviewed so that process is sufficiently sensitive to allow student with a ABI/TBI to get the support they need. Recommend that DET and neuropsychological clinicians get together to put together a more strategy to look at how the testing numbers are used and the rationale behind using scores without using the clinical interpretation

f. Children with a brain injury can get assessment results within the intellectually normal IQ range, but have severe limitations in executive functioning, reduced attention and concentration, slowed processing and challenges of behavioural and social skill changes which impede their ability to manage at school. Students with brain injury without full scale IQ score < 70 but in presence of specific cognitive and behavioural deficits will need significant support in school, although this group does not readily fall within current criteria. Use of the neuropsychological and speech/language testing tools – not meeting the need of the kids as the results are not being interpreted suitably to capture the true needs of the child – school counsellors will benefit from increased liaison with health professionals administering these tests in their expert area to seek greater clarification of functional need and greater understanding of brain injury.

viii. The current system is ad hoc arrangement by local services. An interagency approach that includes NSW Education, ADHC (children services) and specialist acquired brain injury health services would be welcomed to develop a co-ordinated and systematic state-wide approach to meeting the learning and education needs of students with disability from ABI currently excluded or intermittently accessing essential education support. It is worth noting that Ageing, Disability and Home Care (ADHC), NSW Department of Human Services, has acknowledged acquired brain injury as a diagnostic criteria for ADHC provided and funded services for adults. An interagency agreement involves ADHC NSW Health, brain injury specialist services, mental health, drug and alcohol services to reduce barriers to service access and ensure client needs are met without people falling between the limiting remit and criteria of individual organisations.

ix. There is a lack of transparency in how funding decisions are made. In the instances where a student with a brain injury does meet criteria, it is often challenging to identify how support funding is allocated and difficult at times to influence the use of the funding to meet the specific need of the student with a brain injury. Families and supporting agencies cannot easily determine what criteria have been used by a school to make the decision to fund a student. There appears to be a large difference between the types of support that is provided by schools to students with apparently similar needs. For example, one girl with a physical disability and a Traumatic Brain Injury has had major environmental modifications approved at the school she attends in addition to full-time access to a teacher aide. In contrast other students with similar levels of physical disability (or worse) and Traumatic Brain Injury get almost no teacher aide support. So, it seems like a kind of lottery at the moment as to who will get support in the public schooling system.

In addition workers expressed the following:
Families often express frustration at not having a clearer picture of how the funding translates into everyday help for their child in the school setting (who is providing the support, how and for how much of the day). As an external agency, Brain Injury Services are often not privy to why support is or isn't provided in school. This is extremely frustrating as the rejection for funding does not provide sufficient rationale to assist services to adjust their applications and often then delays the students' legitimate return to school. Funding appears to be dependent on the experience, skills and creativity of the school staff and those who can manipulate the funding and applications for funding. These decisions can result in programs that are part time with reduced school hours with a reliance on families to bridge the gap by providing home based family activities, support and supervision. A lack of school education support can result in disadvantage to the child when they leave school early.

In circumstances where insurance is able to pay for teachers aides there is often reluctance by schools to include these strategies and utilise the time specifically for the injured child.

x. Allocation of funding

It is difficult to sense how much funding gets attached to an individual student to support their needs and how this translates to face to face support. This is a difficulty for Brain Injury Services who are able to advocate for additional funding for students who are compensable or have access to funding from Life Time Care Scheme. Brain Injury workers are required to communicate current support levels and argue for additional funding – without this information justification for enhancement is impeded.

It is understood that schools once they have the funding have some degree of 'flexibility' as to how they use these funds, but can choose to use the funds without consultation and hence miss opportunity to target students with special needs with appropriate intervention and input from health professionals

Students with physical needs often easier to gain services because the disability is more concrete and visual but it is the longer term implication of the cognition etc that needs in class support in the long term

xi. Language Criteria

There are an insufficient number of classes and too few students that meet the criteria – their skills are too diverse across the board 1st and 2nd percentile. The Speech Pathologists working within BIRP can provide more information if required.

## 2. Level and adequacy of current special education places

It is the experience of the Brain Injury Services of NSW that the overall preference of parents is to have their children return to mainstream classes with suitable support to make this a positive experience.

Where this is not possible due to the nature of the student's disabilities, or where there is a lack of appropriate support in mainstream schools, Brain Injury Services across NSW have experienced greater difficulty placing students with significant sequelae following their brain injury into the school setting due to a decline in the availability of special class & special school placements.

In addition, the options available for an individual student are not always the most appropriate placement to meet their needs but limitations in funding prevents more intensive input for the student in the mainstream school setting. This has been noted particularly in:

- IM classes,
- behavioural units
- tutorial centres

The removal of specific support classes for students with Mild intellectual disabilities and language-based difficulties continues to present a challenge.

## 3. Adequacy of support services for children with a disability in mainstream school classes

i. Access to in school support:

   a) Parents (and health professionals) unfamiliar with education supports within local and regional levels. In some cases staff within the schools are unaware of their own resources beyond school counsellor.

   b) Heavy load (within and across schools) of school counsellors limits access.

   c) Over reliance on provision of teacher aides in preference for other forms of resourcing e.g. teacher training, teacher release, modified curriculum. Risk for children who have aide support for a long time to become dependent on the one to one support. In some of our complex cases teacher aide has guided the development of the child's program rather than supported implementation of the teacher's program. Usually due to limited knowledge, time and very slow progress of the child.

   d) Parents (and health professionals)are unfamiliar with education supports within local and regional levels. In some cases, staff within the schools are unaware of their own resources beyond the school counsellor.

ii. Process of Applying for School Support

a) The point of return to school after acquiring a severe brain injury is a vital and very demanding time on both the returning student, their school and family. Efficient and forward, cooperative planning is the key to the success of this transition. Frustration continues to be expressed by both health care workers and school staff regarding the limitations imposed on applying for appropriate funding to meet the needs of students with an acquired brain injury and facilitate timely return to school.

b) Many times where the student with a brain injury with ‘return-to-‘ school support needs does not meet and cannot be made to ‘fit into’ the funding criteria, the undesirable situation arises where:

  - Students are returned to school without sufficient support in place. This may mean a teachers and class needs to adjust to the returning student with out extra help in class. The returning student must struggle in class without the physical support of a worker to help with the adjustment process (social, physical, behavioural and cognitive).
  - Students may be delayed from returning to the school system in a time frame that suits their abilities

a. Health care organisations should be able to submit applications for funding support on the **<u>basis of the functional needs of the student</u>** for which they are advocating, **without applications being blocked** for consideration because the student does not fit the limited criteria currently accepted by Department of Education. Allowing all applications for support for consideration allows the DET to develop a broad understanding of the complexity of needs that their school communities are reporting and allow them to plan and provide for services accordingly. The criteria should be flexible enough to cope with applications from specialist health services.

iii. <u>School Support roles</u>

a) <u>Learning Support Officers (LSO) /Teachers Aides</u>

There is great support from Brain Injury Services of NSW to maintain learning support officers/teachers aides in the school setting as they provide the intensive one to one support that a child with a significant brain injury benefits from in the classroom. While there is not empirical evidence that provision of an in class teacher support worker can provide better learning outcomes for the student, the aides do provide a range of outcomes that benefits the student in the schools setting and supports the teachers and other students in that placement. They:

- Implement range of educational & therapeutic programmes under supervision of teacher and therapists
- Allows the teacher to target specific learning areas with greater intensity and opportunity for revision
- Psychologically enhances the child's positive experience of school
- Helps child to access the school environment & curriculum e.g. safety, movement around school, social support, cognition, behaviour, physical, personal care, task initiation, learning at the students pace
- Where augmentative aids do not meet the needs of the student e.g. slowed writing/typing provision of a scribe assists the student stay engaged and on task
- Mental health outcomes

However there is much room for improvement and enhancing the current system of providing LSO to students with special needs. Some concerns raised by clinicians include:

- Lack of transparency in how the recruitment of LSO takes place and what formal training and support is given to staff in these positions
- Unclear how much training teachers have in how to maximise the presence of a LSO in the classroom. Opportunity to enhance teacher training in how to use an aide and work with therapy services.
- LSO where not adequately supported can 'over step' their boundaries with the student – training, supervision and support would assist to minimise this
- Recommend schools take opportunity to train aides specifically about acquired brain injury and the strategies that can be employed to support the student and enhance the intervention of the workers e.g. The Children's Hospital Westmead invites teachers, LSO s and schools counsellors of NSW to a Teacher Education Day each year. A combination of teaching and practical strategies to support the student**.**
- There does not seem to be any formal initial or ongoing support / training for aides in school. Without clear understanding of the nature of brain injury, it is very difficult for the educational worker to facilitate learning and maximise the participation of the student in that environment**.**

b) <u>Specialist School Counsellor (SSC - Brain Injury)</u>

Brain Injury Services NSW have worked with several educational staff in the role of SSC (Brain Injury). This role has proven itself to be a keystone in the vital interface between the health system and the Department of Education. The role enhances both health worker understanding of the educational options and process and similarly provides Educators with a colleague with enhanced skills in understanding how a child with a brain injury can re-enter the school system.

The Acquired Brain Injury Specialist Counsellor, Jean Kidd, provides a valuable role in the provision of appropriate support to the student with a brain injury starting or returning to school. The SSC (Brain Injury) is a very strong advocate of students following a brain injury – the SSC (Brain Injury) understand the complexity of brain injury outcomes and long terms support needs and offers an important interface with the Department of Education system. The role assists workers in both educational and health areas to clarify terminology and understand the constraints of their respective systems, and allows both to work cooperatively towards the best educational and rehabilitation outcomes for the student with a brain injury**.** Currently this role is very limited and there is inequity of access across NSW to this specialist support within schools.

### iv. DET developments regarding school supports

Inviting health services such as the NSW Brain Injury Rehabilitation Programme to participate in formal consultation processes regarding managing the needs of students with disabilities would support collaborative working.
e.g. BIRP would have welcomed the opportunity to respond to and understand the " School Learning Support Program" which was out for consultation in mid 2009:
http://www.schools.nsw.edu.au/media/downloads/schoolsweb/studentsupport/programs/disability/consultation.pdf

## 4. Provision of suitable curriculum for intellectually disabled and conduct disordered students (discuss cognitive impairment)

- Difficulty accessing modified curriculum due to:
  - Lack of teacher experience/ skills (see above)
  - Life skills curriculum not available in primary school
  - Eligibility criteria in high school relies on IQ score or diagnosis of mental illness – criteria too rigid to meet needs of most students with ABI/TBI
- Lack of flexible attendance models for students. Limited options to enrol part time in mainstream and special schools.
- Inadequate transition planning for school leavers. (We acknowledge that there are some fantastic Transition Coordinators employed through DET however in many cases students are not referred proactively to prepare well in advance for transition).

- Inflexible curriculum for early or extended access to work experience.

### 5. Access to professional support services, such as speech therapy, occupational therapy and school counsellors

- Allied health not employed (or contracted) by education in NSW; therefore rely on individual children accessing health or ADHC services. The cut off ages at many community health centres prohibits access for older primary and high school students.
- Inconsistent lines of communication across schools – who should be contacted? Who needs to be involved in meetings etc
- Health, ADHC and education work under different models, use different language. There are limited opportunities for interagency training to improve awareness of resources (within and external to education, improve collaborative working relationships, share understanding of disability, develop collaborative approach to supporting the student.
- In some cases this results in outside services being seen as additional to the students learning support team leading to lack of collaboration, duplication or different directions.

### 6. Adequacy of pre-service and post-service teacher training

- Many teachers lack relevant training and do not have skills to develop modified curriculum for individuals. They have difficulty identifying individual learning goals when the student is unable to achieve class learning goals. Many of our schools look to therapists to guide development of individual education program. Therapists lack sufficient knowledge of curriculum to do this.
- Teachers have limited knowledge of alternative behaviour management strategies. Limited access to specialist behaviour teachers.
- Need for increased access to training and support for teacher aides.

Training for education staff is outside of our area of expertise, however there would be a benefit of formal under and post –grad training in the area of Acquired Brain Injury with specific input from clinical rehabilitation teams providing some education, strategies and real examples of students entering the education system after a severe injury. NB: The Children's Hospital Westmead invites teachers, LSO's, schools counsellors and other teaching staff of NSW to a Teacher Education Day each year. A combination of teaching regarding acquired brain injury, the range of outcomes and practical strategies to support the student. It is envisaged that increased teacher awareness of ABI issues would enable education staff to be more proactive in identifying both the needs of individual students and appropriate resources and strategies to meet the needs of these students at an individual, school and regional level given the education context which rehabilitation staff won't be fully aware of.

Note that access to training package for those working with people with brain injury using web based system is scheduled to be made available to ADHC staff across NSW. This will include at least 2 modules relevant for paediatric brain injury specifically. A similar option for education staff could be explored as a relatively low cost readily accessible system for teachers. Thus would address the issues raised above where, “The BIRP clinicians report that overall in NSW there is not a consistent, nor accurate understanding or a sound **knowledge base** of the nature of acquired brain injury. As a result, the multi-faceted and complex, long-term needs of students with a brain injury are often not met consistently within the public and private education system”.

## 7. Other Issues identified by NSW BIRP

a) Communication within schools:

Communication regarding the needs of children with brain injury can be variable. Scenarios may include:

- Where there is a relief teacher for a mainstream class information about the student with special needs may not be passed on
- Dissemination of information particularly in high schools where many teachers are involved.
- BIRP workers are not always included in Individual Education Plan (IEP) planning and review meetings.

Numerous strategies are implemented in a range of schools to tackle these issues – however there is not a consistent policy that is implemented to ensure that communication stays at an optimum level – consistent policy implementation in both special and mainstream school and across primary and secondary levels would strongly enhance the provision of support to the student with special needs.

A known and recommended procedure adopted state wide would additionally assist external service providers such as Brain Injury Services to interact with the correct school personal and engage the correct applications as it interacts with schools across NSW. Vital roles such as the Specialist School Counsellor, Brain Injury provides an important buffer and support between the health and school system.

b) Positive Interagency Experiences

- Schools are generally very welcoming – the model of working in partnership is strongly advocated by BIRP workers
- Dept of Education and education staff in independent and private school are overall very willing to work with external staff e.g. therapy / BIRP
- School based meetings work well and allow BIRP staff to access a number of key school staff at one time
- Collaboration completing assessments such as ACES, other non standardised checklists to support rehabilitation.
- BIRP workers value the opportunity to work collaboratively and cooperatively for the needs of the children to enhance participation, access to curriculum and functioning outcomes e.g. IEP, pre-enrolment meetings etc
- Schools that allow health workers and therapists to provide direct support and information giving to the teacher and teacher’s aide

facilitate the quality of the information exchanged and allow both parties to work in a responsive timely manner.

- BIRPS can cite many positive experiences where the school has provided physical space to allow for therapy services to occur in the school setting and have then taken direct interest in the intervention – a better model than those wanting the student removed and 'fixed'

## APPENDIX 1: Taken from the "NSW Department of Education and Training DISABILITY CRITERIA (school sector) May 2003".

**Language:** Students must have an assessed receptive or expressive language disorder which is documented within a current speech pathologist's report (in general, the report should be less than 12 months old). At least one of the scales (either receptive or expressive) must indicate a standard score of 70 (second percentile) or less.

**Physical Disability:** The student must have a current physical condition involving the motor system that significantly limits the student's level of functioning and independence in mobility, personal care, and/or ability to physically undertake essential learning tasks.

**Intellectual Disability:** To meet criteria for intellectual disability, students must have a full-scale IQ score on an approved individual test of intelligence of approximately:

- two to three standard deviations below the mean for mild intellectual disability
- three to four standard deviations below the mean for moderate intellectual disability
- four standard deviations or more below the mean for severe intellectual disability

There must be information on the assessment of adaptive skills and school performance (where applicable) consistent with, or below this range of scores.

**Hearing Impairment:** Students must have a current audiogram and report from *Australian Hearing* which indicates a sensori-neural or permanent conductive hearing loss of 30 decibels or more in both ears.

**Vision Impairment:** Students must have a current diagnosed vision impairment, which details a permanent vision loss that is 6/24 or less in the better eye corrected, or less than 20 degrees field of vision.

**Deaf/Blind:** Students must have a vision and hearing impairment, both at levels that severely impact on their ability to learn, and which result in unique educational needs.

**Mental Health Problems:** Students must exhibit behaviour(s) that is characteristic of mental health problems at a level of frequency, duration and intensity that seriously affects their educational functioning and emotional well-being. The behaviour(s) must be evident in the home, school and community environments.

**Autism:** Students with autism must have a current report from a specialist medical practitioner or registered psychologist with appropriate clinical experience.

### General Notes

Where there is evidence that a student has a significant disorder or malfunction that is not adequately described by one or more of the above criteria and the condition is impacting greatly on educational outcomes, the Coordinator Student Counselling and Welfare together with the Coordinator Special Education will consider all available documentation and make a determination on a case by case basis.

When considering support class placement for students with more than one disability, it is important to ensure that the disability having the most significant impact on educational outcomes is addressed and any other disability supported in an appropriate manner.

## APPENDIX 2: Background to the Academic Competence and Evaluation Scales (ACES).

The ACES has robust psychometric properties and has been developed in accordance with the Standards for Educational and Psychological Testing which is published jointly by the American Educational Research Association, American Psychological Association and the National Council on Measurement in Education (Di Perna and Elliot, ACES Manual, 2000). It was primarily designed for teachers and school based practitioners, along with community staff to support work with children and adolescents. The Academic Competence Evaluation Scale or ACES[4], needs to be rated by the teacher or teachers involved with the student. It is scored by the rehabilitation clinician but joint interpretation is recommended.

The ACES has 73 items which measures the teachers perception across two domains, Academic Skills, related to academic performance which are taught explicitly in the classroom including reading, maths and critical thinking, and Academic Enablers, which are skills and behaviours that support academic performance (e.g. study skills (e.g. paying attention in class, completing homework), interpersonal skills, engagement (e.g. volunteering in class, assuming leadership) and motivation (e.g. persists when task is difficult). The teacher does not need to score the form. The items are rated according to the proficiency or frequency of a behaviour, skill, or attitude compared to grade level expectations over the past month rated the importance of the behaviour, skill, or attitude in each teacher's classroom.

We hope to evaluate whether the ACES provides clinically useful information that can also be objectively analysed. Information from the ACES will provide:

- Objective information on how a child is currently performing academically and in the school community.
- Support clinical reasoning to identify the rehabilitation goals the client wants to achieve at home and in the classroom and what intervention/ support will assist goal achievement.
- Enable a student's progress to be monitored over a school year

The ACES is completed by the child's teacher who rates the child's participation in the classroom which takes around twenty minutes to complete.

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[4] DiPerna and Elliot (2000)

## APPENDIX 3: References

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