

# BRAIN INJURY AUSTRALIA

## Submission to the Productivity Commission's Inquiry into Disability Care and Support

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## EXECUTIVE SUMMARY

Brain Injury Australia welcomes the Productivity Commission's Inquiry (the "Inquiry") and the recognition that the current system is flawed and in need of radical overhaul. The fact that people with disabilities, their families and carers have been consistently failed and overlooked is recognised in the Productivity Commission's Issues Paper (the "Issues Paper") and Brain Injury Australia strongly supports action that will lead to the implementation of a new "national disability scheme". In particular, Brain Injury Australia considers that a national disability insurance scheme ("NDIS"), as recommended by the Disability Investment Group ("DIG"), would be an important contribution in designing a new system that is effective, efficient and above all, fair.

Brain Injury Australia has also taken note of the National Disability Strategy Consultation Paper "Shut Out: The Experience of People with Disabilities and their Families in Australia", the draft submission of the Australian Federation of Disability Organisations and the submission of the Australian Human Rights Commission ("AHRC").

In responding to this Inquiry, Brain Injury Australia has not attempted to address each question in the Issues Paper, rather focus on particular issues which it believes are the most relevant to people with acquired brain injury ("ABI"), their family members and carers. This submission reflects a collective consultation with our Member Organisations in New South Wales, Queensland, Tasmania, South Australia, Victoria and Western Australia. In addition to our collective submission, State and Territory-specific submissions are being prepared by our Member Organisations in South Australia, Victoria and Western Australia.

Brain Injury Australia makes the following recommendations:

- 1) **Need is a more appropriate basis for eligibility than one based on a medical diagnosis.** A nationally consistent definition of need must be developed, which retains flexibility to respond to the complexity and diversity of different disabilities, including acquired brain injury.
- 2) **The following groups of people living with an ABI have the highest needs or have been most disadvantaged by current arrangements:**
  - a) Those with a "dual diagnosis" of ABI and mental illness;
  - b) Aboriginal and Torres Strait Islander communities;
  - c) Those living in regional, rural and remote areas;
  - d) The homeless;
  - e) Those in the criminal justice system; and
  - f) Those with alcohol and other drug-related brain injury.
- 3) **'Severe' or 'profound' disability is an appropriate criterion for the need for support,** given the requirement for any scheme to be financially sustainable and practical. Brain Injury Australia draws the Commission's attention to the minority of people with a "mild" traumatic brain injury ("TBI") who will experience long-term and debilitating cognitive and other impairments who should be eligible for support under any proposed "national disability scheme".

- 4) **Assessment tools should be flexible and nationally consistent.** Brain Injury Australia understands that a number of nationally available, scientifically verifiable tools are available which would be appropriate for any assessment process.
- 5) **The needs of carers of people with an ABI should be factored into eligibility.** Carers play a pivotal role in rehabilitation and significant savings to the cost of a new scheme can be made if informal carers are appropriately supported.
- 6) **The “national disability scheme” should only extend to those people with a ‘severe’ or ‘profound’ disability aged less than 65 years** (increasing to 67 by 2017 in line with the Age Pension qualifying age).
- 7) **The “national disability scheme” should be comprehensive and cover both the existing eligible population as well as new “cases of disability”.**
- 8) **Individualised funding should be available to all people with a disability** with the necessary supports made available for those who may require assistance in planning their service requirements.
- 9) **A new national framework of service structure needs to be established which sets minimum standards for delivery in each state, ensuring consistency of treatment and support for all people with a disability. Under this framework the most important services for people with ABI are:**
  - a) early intervention and rehabilitation;
  - b) individualised case management; and
  - c) ABI-specific training.
- 10) **Service providers should be monitored through reputable, independently audited, quality systems,** which when combined with individual client feedback forms can provide a comprehensive reporting and accountability process.
- 11) **Community-level education and awareness-raising of ABI will increase the likelihood of participation in the work and the community.**

## OVERVIEW OF ACQUIRED BRAIN INJURY

### BACKGROUND: ACQUIRED BRAIN INJURY

ABI refers to the multiple disabilities arising from any damage to the brain that occurs after birth. That damage can be caused by an accident or trauma, by a stroke, a brain infection, by alcohol or other drugs or by diseases of the brain like Huntington's disease. TBI refers to an injury the result of force applied to the head from a motor vehicle accident, a fall or an assault.

The international literature recognises that ABI is a leading and increasing cause of disability worldwide. It is ten times more common than spinal injury and produces, on average, three times the level of disability.

### EFFECTS OF ABI

Because it is the brain that is injured, people with an ABI can experience a range of disabilities that will affect them both physically and also in the way they think, feel and behave. Damage to an organ which is not completely understood and is unique in every human being results in disability which is as variable as the brain itself, meaning that no two people with an ABI should be regarded as the same.

Physical disabilities can include headaches, fatigue, seizures, poor balance and coordination, paralysis, loss of the sense of taste or smell and vision or hearing disturbance. Many people with an ABI live with cognitive disability such as poor memory and concentration, a reduced ability to learn, to plan and to solve problems. In addition, almost two out of every three people with an ABI will exhibit shifts in their behaviour including increased irritability, poor impulse control, verbal and sometimes physical aggression<sup>1</sup>. These behaviours are often due to damage to particular areas of the brain. However, they can also have been learned or adopted as a response to disability.

People with ABI tend to have complex disability: the Australian Bureau of Statistics' 2003 Survey of Disability, Ageing and Carers (the "ABS Survey") found that people with an ABI reported more disability groups and health conditions when compared with all people with disability. They are also much more likely to need assistance with the basic tasks of everyday life: self-care, mobility, meal preparation, paperwork and so on when compared to people with other disabilities.

## PEOPLE WITH AN ABI

Over 500,000 Australians have an ABI:

- three out of every four are aged less than 65;
- as many as two out of every three acquired their brain injury before turning 25; and
- three out of every four are men<sup>ii</sup>.

### Traumatic brain injury – a prime of life disability

Over 22,000 Australians were hospitalised due to a TBI during 2004-2005<sup>iii</sup>. Most - over two in every five - were caused by a fall, nearly one in three due to a motor vehicle accident and one in six from an assault<sup>iv</sup>.

Unlike many other disabilities, TBI often occurs in the prime of life, with two out of every three people experiencing their TBI before they turn 25<sup>v</sup>. The disabilities that result can fundamentally alter a person's sense of self, right at the point when they are launching into adult life: leaving school or home, completing further education or starting employment. As many as nine out of ten people who sustain a "moderate" to "severe" TBI are returned to the care of their family. Coming to terms both with disabilities that may affect almost every aspect of living, and with the grief for changed or lost abilities is perhaps the central challenge of recovery from TBI.

Return to work will often prove difficult as people with an ABI take more time and need more support than other people with disabilities to achieve meaningful and sustainable employment. They have the second lowest representation (after autism) of all people with a disability in employment, with one Australian study finding that only 40% of people with ABI were employed five years post-injury<sup>vi</sup>. However, they are also less likely than people with other disabilities to use employment services<sup>vii</sup>. Setbacks to rehabilitation, such as failure at work, can sometimes result from unrealistic expectations and lack of awareness of impairments. Recovery takes time and it will only be through the persistence and patience of the injured person and the assistance of carers, family members, service providers and the broader community that the individual can create a new life that satisfies their goals and ambitions.

Due to the changes in the way people with a TBI often see themselves, and in the way they are seen by others close to them, profound changes in relationships are also common. Half of people with a TBI report having lost friendships and becoming more socially isolated since their injury. One study found that almost half of those interviewed had divorced or separated from their partners within an eight year period following TBI<sup>viii</sup>.

Brain Injury Australia would argue that disabilities "acquired" in circumstances such as those described above warrant a different understanding in any proposed "national disability scheme". Brain Injury Australia is not advocating that ABI be treated more *favourably* than any other disability. Rather it asks the Productivity Commission to be aware of the particularities of ABI that make it often an almost unique disability. These include: the psycho-social adjustment to life post-injury; the cognitive-behavioural disabilities that can result in isolation and ostracism from friends and family; and societal fears of what injury to the brain might mean - akin to

the prejudices that may apply to mental illness or autism, but not to more widely recognised physical, sensory or intellectual disabilities.

### People with a mental illness

Studies have shown that up to two out of every three people who have experienced an ABI may develop a major mental illness over the course of their lifetime<sup>ix</sup>. Depression, anxiety disorders, mood and personality disorders, schizophrenia and panic disorders may all be present after an ABI<sup>x</sup>. In addition, they are at a higher than usual risk of suicide than the rest of the population<sup>xi</sup>.

### Aboriginal and Torres Strait Islander communities

There has been very little research into the prevalence of ABI amongst Aboriginal and Torres Strait Islander (“ATSI”) populations. However, estimates indicate rates up to three times that of non-ATSI communities. One study has shown that the rate of head injury<sup>xii</sup> due to assault among ATSI communities was 21 times higher than the equivalent rate for non-ATSI Australians (854 per 100,000 compared to 40.7 per 100,000 for the non-ATSI population)<sup>xiii</sup>.

### Criminal justice system

Many studies have examined the link between ABI and offending<sup>xiv</sup>, although they remain equivocal as to whether ABI itself is the cause of the offending behaviour or whether the life circumstances of those offenders who subsequently report ABI are perhaps criminogenic. Studies have shown that ABI prevalence among prisoners ranges from 25%<sup>xv</sup> to 82%<sup>xvi</sup>. The 2001 New South Wales Inmate Health Survey found that 39% of women and 45% of men surveyed had sustained a head injury at some point in the past that resulted in significant loss of consciousness<sup>xvii</sup>.

### The homeless

A number of local surveys have attempted to estimate the number of people with an ABI who are homeless. A 1998 “Down and Out in Sydney” project found that 10% of people using inner city Sydney hostels and refuges had cognitive impairment as a result of alcohol-related brain injury or TBI. Two Victorian studies of pension-only Supported Residential Services pointed to the high proportion of residents with ABI; 13% and 17%. A study conducted by Ozanam Community Support Services Outreach Program detailed that over the three year period – 1997 to 2000 - 33% of clients had a diagnosed alcohol-related brain injury.

### Alcohol and other drug-related brain injury

The prevalence of alcohol and other drug-related ABI tends to be underestimated as only a minority of alcohol-related brain injury cases are diagnosed prior to death. Furthermore, alcohol and other drug abuse carries with it a stigma, which may discourage individuals from seeking treatment. Taking into account these caveats, it is estimated that nearly 4 per cent of men and 3 per cent of women drink at levels putting them at high risk of long-term harm to their health, including brain injury<sup>xviii</sup>. The problem is particularly marked amongst rural, remote and ATSI communities. Again, data are hard to come by, however, a recent Senate Report recorded 60 ATSI deaths in the Northern Territory and 120 people in Central Australia with permanent brain damage as a result of petrol-sniffing alone<sup>xix</sup>.



## THE “HIDDEN”, THE “INVISIBLE” DISABILITY

Brain Injury Australia welcomes the commitment in the Issues Paper to extend support to those who languish on the outskirts of service provision. However, Brain Injury Australia is concerned that this commitment may be undermined by the Commission's faulty presupposition: that people with a disability comprise a coherent population who know both their disability and their needs arising from it and can express those needs for the purposes of receiving disability services and support. This is fundamentally misguided, and there are individual and social contexts specific to ABI that are relevant.

ABI is often referred to as the “hidden” or “invisible” disability. This operates in at least four ways. First, at a population level: in official estimates of prevalence significant numbers of Australians with an ABI are simply unknown to government. For example, one of the fundamental documents in estimating the prevalence of disability in Australia, the ABS Survey, significantly underestimates the number of people living with an ABI. The ABS Survey's sample comprised “14,000 private dwellings and 300 non-private dwelling units”, covering “people in both urban and rural areas in all states and territories, except for those living in remote and sparsely settled parts of Australia.” [underline added] Estimates of the prevalence of ABI in ATSI communities generally, and in the Northern Territory specifically (where Aboriginal and Torres Strait Islanders comprise 30% of the population) indicate rates up to three times that for non-ATSI communities. Furthermore, the ABS Survey had no capture of the criminal justice system or homeless Australians. The ABS Survey estimated that 432,700 Australians (2.2% of the population) had an ABI with “activity limitations” or “participation restrictions” because of their disability. Due to the deficiencies in the ABS Survey's sampling, Brain Injury Australia is confident that over 500,000 Australians have an ABI.

Secondly, due to the severity, multiplicity and complexity of disability experienced by people with an ABI, or the circumstances in which their brain injury was acquired (chronic alcohol or other drug abuse, for example), many individuals “hidden” from such government surveys may not know that they have a disability.

Thirdly, due to the circumstances in which their brain injury was acquired, or as a function of the resulting disability, many people with an ABI may have a reluctance to disclose their disability. For instance, they may blame themselves for a moment's inattention at the wheel of a car, or are ashamed from the stigma attached to drug or alcohol abuse. Feelings of embarrassment, guilt or shame are powerful deterrents to talking openly about disability. The ABS Survey recognised this: “A number of people may not have reported certain conditions because of: the sensitive nature of the condition... [and] a lack of awareness of the presence of the condition on the part of the person reporting...” Also, “the need for help may have been underestimated, as some people may not have admitted needing help because of such things as a desire to remain independent...”.

Fourthly, lack of societal awareness compounds the problem. The majority of people with an ABI make a good physical recovery and often the injured person will show no outward signs of disability. The common effects of injury, such as poor short-term memory, fatigue or irritability can be misinterpreted as simply flaws in the person. People are often mistaken as drunk, unintelligent, uncooperative, unmotivated or alternatively aggressive and unpredictable. Brain Injury Australia believes that public

understanding of ABI lags around 20 to 30 years behind that of other disabilities. Such a lack of public understanding of ABI is doubly disabling for the person affected: not only are these “invisible” disabilities not recognised as resulting from an ABI, they are seen as a function of who the person really is.

As a measure to improve the “visibility” of people with an ABI at the level of population, Brain Injury Australia is grateful that the July, 2008 Community and Disability Services Ministers’ Conference agreed to inject \$6.5 million to enhance the next iteration of the ABS Survey, including doubling the sample size (due for release in 2011). But if the Australian Government is serious about creating a genuinely “national disability scheme” it needs to know the full extent of the population to whom it is responsible under the United Nations Convention on the Rights of Persons with Disabilities (“CRPD”). As the DIG noted, governments in Australia spend over \$25 billion on disability each year<sup>xx</sup>. Yet there is virtually no investment in disability-related research, including surveys of ABI prevalence, such as in the populations listed above. Moreover, research is the only way that evidence-based policy and best practice can be developed leading to substantial cost savings for any proposed scheme.

As a means of improving the “visibility” of people with an ABI at a community level, awareness-raising and cross-disability education is essential. That is a key obligation of the States Parties under Article 8 of the CRPD who have undertaken “to adopt immediate, effective and appropriate measures” which include “initiating and maintaining effective public awareness campaigns...”<sup>xxi</sup>. Brain Injury Australia endorses the AHRC’s recommendation that institutions administering an NDIS or similar scheme be empowered to undertake and fund awareness raising measures in accordance with Article 8 to address attitudinal barriers.

An increase in demand for resources will be a natural consequence of raising awareness among people with an ABI who remain outside the disability services system. Given the “invisibility” of ABI, will the Australian Government be prepared to shoulder the additional responsibility for the potentially thousands of people whose “awareness” of their ABI has been “raised” as a result of community education strategies? In addition, if any proposed “national disability scheme” was to be truly “no-fault”, would it include people whose ABI is self-inflicted as the result, for example, of chronic alcohol or other drug abuse?

## ABOUT BRAIN INJURY AUSTRALIA

Brain Injury Australia is the national peak ABI advocacy organisation representing, through its State and Territory member organisations and network relationships, the needs of people with an ABI, their families and carers. The major components of Brain Injury Australia's role are:

- advocacy for Australian Government program allocations and policies that reflect the needs and priorities of people with an ABI and their families; and
- the provision of effective and timely input into policy, legislation and program development through active contact with Australian Government ministers, parliamentary representatives, Australian Government departments and agencies, and national disability organisations.

Brain Injury Australia is made up of its Member Organisations:

- Brain Injury Association of New South Wales;
- Brain Injury Association of Queensland;
- Brain Injury Association of Tasmania;
- Brain Injury Network of South Australia;
- Headwest (Western Australia);
- Brain Injury Matters (Victoria);
- Victoria Coalition of ABI Service Providers; and
- Somerville Community Services Inc (Northern Territory).

## SCOPE OF THIS INQUIRY

The Productivity Commission has been asked to undertake a public inquiry into a long-term disability care and support scheme. Amongst other things, this Inquiry will examine:

- how a scheme should be designed and funded to better meet the long-term needs of people with disability, their families and carers;
- how to determine the people most in need of support, the services that should be available to them, and service delivery arrangements;
- the costs, benefits, feasibility and funding options of alternative schemes;
- how the scheme will interact with the health, aged care, informal care, income support and injury insurance systems;
- its impacts on the workforce;
- how any scheme should be introduced and governed; and
- what protections and safeguards should be part of the scheme.

This Inquiry is as a result of recognition that attitudes and approaches to disability have experienced a paradigm shift in recent years. Disability is now a social responsibility, not an individual's medical problem. It results from the interaction between a person with an impairment and their environment, a non-inclusive society, rather than being defined simply by diagnosis or cause<sup>xxii</sup>. Three recent developments will direct Australia's approach to disability reform: ratification of the CRPD; the National Disability Strategy ("NDS") and the National Disability Agreement ("NDA").

Having ratified the CRPD in 2008, the Australian Government now has a responsibility to ensure that its principles and obligations direct and underpin disability policy, service planning and delivery. The Australian Government must continue to set the example to other developed countries as to the true aspiration of this Convention: quality of life for all people with disabilities. We have moved well beyond the stage, both medically and socially, where people with disabilities should be prepared to accept less than others, to merely subsist and survive. The Australian Government must now remove all barriers to people with disability that may "*hinder their full and effective participation in society on an equal basis with others.*"<sup>xxiii</sup>

The NDS was a key recommendation of the 2007 Senate Inquiry into the funding and operation of the Commonwealth State/ Territory Disability Agreement ("CSTDA"). It will be crucial in determining what policies and programs are necessary in order to ensure that the principles enshrined in the CRPD are upheld. Brain Injury Australia understands that it will be informed by both the views in the report, "Shut Out" and also the recommendations of the DIG report, "The Way Forward: a New Disability Policy Framework for Australia".

The third development was the introduction of the new NDA, on 1 January 2009, which replaced the 2002-2007 CSTDA. This provides the national framework for the provision of services for people with disabilities and together with the CRPD and NDS will set the remit for development of disability policy.

## “WHO SHOULD BE ELIGIBLE?”

### *“Is need the appropriate basis for eligibility?”*

Brain Injury Australia believes that need is a more appropriate basis for eligibility than one based on a medical diagnosis. The latter is too rigid and simplistic when applied to ABI, which for many can be undiagnosed, and where the resultant disabilities can cross many domains: physical, sensory, cognitive and behavioural. Any assessment process must be shaped by the impact on the person's ability to undertake activities of daily living. Eligibility based on a “one-size-fits-all” diagnosis would lead to inappropriate treatment and service provision, wasted resources and the continued exclusion of significant groups of people with an ABI.

However, need cannot be entirely divorced from a diagnosis and ignoring a type/diagnostic group would not be advisable. As discussed above, this is especially important for those who may not know that they have an ABI, or be able to assess their needs arising from it, or for those who are inhibited from advocating to have those needs met.

Equality of access to the scheme is essential and therefore a nationally consistent definition of need, which retains enough flexibility to respond to the complexity and diversity of different disabilities, must be developed and applied .

### *“What groups have the highest needs or have been most disadvantaged by current arrangements?”*

#### **“Dual Diagnosis”**

There are several types or combinations of disability that come under the heading “dual diagnosis”, one of which is ABI and mental illness. The cognitive-behavioural and psychiatric problems, while often the consequence of ABI, can also mask it and in some people it is impossible to separate whether a presentation is due to ABI, or mental illness, or both.

It is Brain Injury Australia's experience that people with a dual diagnosis of ABI and mental illness are regularly either refused assistance by mental health services or, where they are accepted by a mental health service, they may receive treatment for their mental illness, but have their ABI ignored. Receiving the wrong intervention can exacerbate mental illness, jeopardise recovery from ABI and result in the person with an ABI being “bounced” between services. For example, “dual diagnosis” is common with prisoners, where *“it is well-established that people with mental illness are incarcerated at a higher rate than the general population... (Senate Committee on Mental Health 2006, Butler et al. 2005)”*<sup>xxiv</sup>.

### Aboriginal and Torres Strait Islander communities

While ABI prevalence estimates for ATSI communities are three times that of non-ATSI communities, their true rates can really only be guessed at. In addition, while data collection on ATSI disability has continued to improve, questions remain as to whether disability surveys are culturally relevant. That ATSI communities may have a concept of disability that is dramatically different from non-ATSI communities is illustrated by surveys conducted by the Australian Bureau of Statistics. In these *“Indigenous Australians tend to report similar or better health than other Australians. However, more ‘objective’ measures of health status, such as standardised mortality ratios and life expectancy, indicate that Indigenous people have substantially poorer health than other Australians (Mathers 1996)”*. Self-assessment questionnaires can lead to these communities falling between the gaps as they would not label themselves as disabled and in need of support. Any new “national disability scheme” needs to avoid this trap and promote research into developing a more sensitive and accurate data collection. Also, the “gold standard” for assessment of ABI is a neuropsychological assessment by a suitably qualified professional. There is still a profound lack of culturally appropriate and sensitive assessment tools in this area<sup>xxv</sup>.

### Regional, rural and remote communities

The overrepresentation of people with an ABI in regional, rural and remote communities combined with the geographic disadvantage of distance and access to specialist brain injury rehabilitation programmes has resulted in these communities experiencing significant unmet need under the current service arrangements.

### The “invisible” population

Brain Injury Australia draws the Commission's attention to those additional groups detailed (on pages 4 and 5, above) that comprise the populations of people with an ABI who remain “invisible” to government. The DIG recognised that better-managed care and support for the homeless and those in the criminal justice system should lead to reduced incidence of disability relating to homelessness, crisis accommodation, child protection, drug and alcohol services, hospitalisation and imprisonment<sup>xxvi</sup>. These potentially significant offsets would need to be taken into account when considering the full costing of the proposed “national disability scheme” and should lead to its long-term sustainability. For instance, given that there are currently 25,000 Australians in prison and that, on average, their per capita cost is \$75,000 per annum<sup>xxvii</sup>, Brain Injury Australia believes that there is no substitute for correct identification, early intervention, more targeted and better funded services and support for detainees with an ABI. This could be in the form of screening specifically for ABI at reception, education of both prisoners and prison workers in ABI and a commitment to in-prison and post-release programs as exercises in crime prevention. In addition, with over 105,000 people reported to be homeless on the 2006 Census night, training should be given to staff working in services to the homeless to help them identify an ABI, especially in someone either unwilling to disclose or unaware of their disability.

*“Is ‘severe’ or ‘profound’ an appropriate criterion for the need for support?”*

Brain Injury Australia recognises that the “Terms of Reference” for this Inquiry indicate that the new “national disability scheme” is not intended to cover all degrees of disability. Therefore, Brain Injury Australia agrees that “severe” or “profound” disability are appropriate criteria for the need for support and would cite the work done by Pricewaterhouse Coopers (“PwC”) in forming a working definition of severity in the context of catastrophic injuries<sup>xxviii</sup>.

However, while we support these criteria as appropriate, given the need for any scheme to be financially sustainable and practical, Brain Injury Australia re-emphasises the disparate and diverse nature of the disabilities that may result from an ABI.

Around 75% of all TBIs are “mild” in nature<sup>xxix</sup>. The vast majority - over 85% - of these “mild” TBIs will result in short-term, limited impairments that resolve within three to six months. The remainder will often experience ongoing and debilitating cognitive and behavioural disability, which fundamentally affects their daily life. Brain Injury Australia believes that any needs-based assessment of eligibility for a “national disability scheme” must include this group.

*“What are the appropriate features of assessment tools?”*

Brain Injury Australia supports an assessment process that is flexible and nationally consistent. The assessment should be made by a panel or using a methodology with input from at least one person with ABI expertise and one consumer representative. The process should be open and transparent to ensure that the outcomes are readily understandable to the person with a disability. The assessment criteria must be measurable and Brain Injury Australia understands that there exist a number of nationally available, scientifically verifiable tools that are currently used which could be appropriate for the assessment process. These include tools that classify by diagnosis and/or functional ability.

*“How should carers’ needs be factored into eligibility?”*

ABI not only impacts on the person, but their surrounding network of family and friends. These are the people most likely to become their carers through providing unpaid assistance and support. The majority of carers of people with ABI are women (a mother or spouse) and relatively young<sup>xxx</sup>. Brain Injury Australia believes that their needs should be factored in as they play a pivotal role in rehabilitation. Studies suggest that social support for carers and developing family coping strategies may improve outcomes for the person with the ABI<sup>xxxi</sup>.

The research evidence is clear that quality of life is seriously compromised by the experience of becoming a carer<sup>xxxii</sup>. Caring for someone with an ABI can be overwhelming both physically and emotionally, with many experiencing trauma, shock and grief following the injury to their loved one. In addition, they may have to adjust to their loved one’s cognitive disabilities and behavioural changes, such as increased anxiety, aggression and self-centredness<sup>xxxiii</sup>. Given the demands on carers’ time, their ability to engage in community activities is reduced<sup>xxxiv</sup>, as is the

frequency of their contact with friends. Many relinquish paid employment resulting in significant financial stress and disadvantage.

Considerable health problems can result: a study has shown that well over half of all carers reported a decline in physical health since becoming a carer<sup>xxxv</sup>. There is an impact on the mental health of family carers, with many experiencing stress, anxiety and depression<sup>xxxvi</sup>. Substance abuse has also been reported as a consequence of caring for someone with an ABI<sup>xxxvii</sup>.

Studies of carers' needs have shown that their requirements change over time, from acute medical and professional supports during the first two years post-injury to an expanded range of services including social supports, financial assistance, and respite<sup>xxxviii</sup>. One study found that only 55% of the needs of carers of a person with an ABI were perceived to have been met<sup>xxxix</sup>.

A 2009 Access Economics report estimated \$25.1 million in "total lifetime carer costs" for a "moderate" TBI and \$28.5 million for a "severe" TBI<sup>xl</sup>. The incidence of family breakdown following ABI is high and could lead to significant "replacement costs" from the formal care sector. Further, without adequate community support and services people have a "carer life" of around five years before the demands of the role cause "burnout"<sup>xli</sup>. Therefore, there are potentially significant savings to the cost of a "nationally disability scheme" if informal care is made sustainable through providing appropriate carer and family support.



## **“WHAT ABOUT NATURAL AGEING?”**

*“How should the scheme address disability associated with natural ageing, and why?”*

Brain Injury Australia supports the option outlined in the Issues Paper; that the “national disability scheme” only extends to those people with a “severe” or “profound” disability aged less than 65 years (increasing to 67 by 2017 in line with the Age Pension qualifying age). This would be a simple and objective criterion and would include ageing-related conditions up to age 65 years and exclude non-ageing related “sources of disability” after age 65 years. This would allow for certainty in budgets and funding. Brain Injury Australia believes that the underlying principle should be that, irrespective of a person's age, if a person has an entitlement to treatment then treatment should be provided.

Therefore, the new “national disability scheme” must develop more supported transitions from disability to aged care services to create certainty for people with disability as they age. For instance, this should include portability of aids and equipments as well as transferability of supports between community-based housing and aged care accommodation. There must be workforce development to ensure that staff are trained to provide the appropriate support and, as outlined below, this should include specialised training in ABI.

## **“COMPREHENSIVE VS NARROW COVERAGE”**

*“Should the scheme apply to new cases of disability or to all people with existing disabilities?”*

Brain Injury Australia supports a comprehensive scheme under which all people who are born with or acquire “severe” and “profound” disabilities before the age of 65 (or other pensionable age) are eligible. Once those people reach the age of 65 they will then be transitioned to the aged care system. In line with the recommendation of the DIG, the scheme should not be restricted to new cases of disability but cover the existing eligible population as well as new incidence.

Brain Injury Australia notes that the DIG has recommended a phased implementation over 7 to 10 years. However, we would caution that, in our opinion, history has shown that transitional approaches to the introduction of new schemes do not work. A point-in-time implementation, such as was employed with Medicare and the Goods and Services Tax, will lead to less confusion and systemic compromise.

## “WHO MAKES THE DECISIONS?”

### Individualised Funding

*“How should the national disability scheme support people’s decision-making under individualised funding, taking account of the spectrum of disability - both in terms of the nature and severity of disability? Should all people be able to access individualised funding, and if not, what guidelines would be appropriate?”*

Brain Injury Australia supports individualised funding for its constituents as upholding the principle of self-determination. Our constituents have disparate and diverse needs and they require a flexible process to allow them to determine how best those needs can be met. Individualised funding grants choice and control: creating independence for people with disability, their families and carers. It will also facilitate a service system that is far more responsive than existing group or block funding models.

This model requires an investment in trust - a move away from the current costly bureaucratic system of micro-management and intervention that is based on a fundamental belief that people with a disability do not have the capacity to make good decisions about their support requirements.

Alongside this, the scheme should recognise that some individuals may require greater support in order to plan and exercise this choice. For some people with ABI, the associated trauma and resultant cognitive disabilities may affect a person’s ability to make informed decisions, to plan and to have insight into what services they may need. However, individualised funding should still be the goal for all, albeit with the recognition that support should be available for those who ask for it.

## “NATURE OF SERVICES”

*“What are the most important services, their costs, their likely demand and who would be the predominant users?”*

The ABS Survey provided information on people with a disability’s need for assistance across ten “life domains”; three core activities (mobility, self-care and communication) and seven “non-core activities”. The findings were that:

- over 100,000 people with an ABI aged under 65 (more than one-third) reported needing help with cognitive and emotional tasks;
- compared with disability generally, people with ABI were more likely to need assistance with mobility, self-care, cognitive and emotional tasks, paperwork, transport and health care and meal preparation; and
- almost 30% of people with ABI aged under 65 years, living in households, needed help with at least one core activity (compared with 26% of people with disability generally) and 4% needed help with all three core activities (compared with 2% of people with disability generally).

### A national framework

The Issues Paper highlights as a “chief target for change” the current inequity of treatment and the inconsistent delivery of services. This is what some call the “postcode lottery” – whereby people with similar levels of functionality may receive quite different levels of support depending on their jurisdiction or the origin of their disability.

For instance, brain injury specific rehabilitation currently depends on where you sustain your ABI. State and Territory Government-funded brain injury rehabilitation services are either “hit and miss” - depending on where you live<sup>xlii</sup>, or the cause of injury and whether it is compensable - or simply non-existent. Overall, there are insufficient services available and those that exist demonstrate little consistency in methodology or practice.

What is needed is a national framework of service structure. This should set minimum standards of treatment and services in each State and Territory to ensure national consistency in access to appropriate medical, rehabilitation and community services. Capacity needs to be built in every state to provide effective pathways for services and interventions based on an individual’s needs from sub-acute rehabilitation through to reintegration in the community. Brain Injury Australia endorses the AHRC’s view that an NDIS should directly address these gaps, limitations and inconsistencies.

In addition, there are currently incomplete links between services provided by different departments such as housing, employment, healthcare, transport and education. Inter-departmental agreements should be established so that services are “joined up” and can address those with more complex needs in a more coherent way.

Brain Injury Australia believes disability services should be life-long and respond to the episodic need for services and support experienced by people with an ABI. The current system does not cater for this, instead favouring short-term, crisis-driven interventions. Once a person leaves a disability service it can be very difficult for them to re-engage and it should not take an emergency for services to become available again. Under a national framework, Brain Injury Australia believes that the following services are the most important to be included in a new “national disability scheme”.

### Early intervention and rehabilitation

The Australian Government has agreed to implement effective and appropriate rehabilitation programmes as detailed under Article 26 of the CRPD. As part of this obligation, early intervention is recognised as a priority and is supported by the Issues Paper, the DIG and the AHRC.

Research into recovery from ABI clearly supports early intervention<sup>xliii</sup>: namely, a comprehensive program of rehabilitation immediately post-injury speeds physical recovery and community re-integration, reduces psycho-social disability and enhances employment prospects, thereby reducing future liabilities of the Australian Government. A caveat to this is that whilst early intervention does bring measurable gains, recovery from a “severe” or “profound” ABI may take considerable time<sup>xliiv</sup> and service support needs will be long-term. This is particularly the case with those who experience an ABI early in life: a study has shown that service use is high even 20-26 years post-injury, with 85% having used at least one service, such as financial, transport, home support in the previous 12 months<sup>xliv</sup>. Therefore, a potential limitation to the emphasis on “early intervention” in the Commission’s thinking could be that the episodic and lifelong needs of people with an ABI will be forgotten. For some people with an ABI, no amount of early intervention will alter those service requirements.

In-patient treatment should focus on issues such as retraining in activities of daily living, pain management, cognitive and behavioural therapies, pharmacological management, assistive technology and environmental manipulation. Many patients also require rehabilitation for associated trauma and therefore counselling should be provided. This should include relationship support services and be extended to family, significant others and friends in order to demystify the experience of ABI. Further, given the frequency of mental illness following ABI, brain injury rehabilitation should include professionals with training in mental health<sup>xlvi</sup>.

In the early stages post-ABI, basic legal and informational supports are required<sup>xlvii</sup> and once discharged from sub-acute rehabilitation the person with an ABI needs assistance to achieve the maximum degree of return to their previous level of functioning. This includes adequate provision of assistance with transport, financial support, home support and medical consultations<sup>xlviii</sup>. However, independence in physical domains is much more common than in psychosocial domains<sup>xlix</sup> and effective community-based rehabilitation is a desperate unmet need. One study has shown that less than half the number of people requiring social participation and vocational services actually receive them (unmet need was 73% and 67% respectively).

The right of people with disability to participate on an equal basis in cultural life, recreation, leisure and sport is recognised by Article 30 of the CRPD. Brain Injury Australia supports the view of the AHRC that the aims of a new scheme should not be confined to survival and subsistence because *“the ability to engage in leisure activities, or any other life roles for that matter, contributes significantly to people’s perceived quality of life.”*<sup>ii</sup>

### **Individualised case management**

Adequate planning, pathways and follow-up after discharge from acute or sub-acute care are unmet needs for people with an ABI. Each individual should have a care and support plan which adopts an evidence-based approach and is able to demonstrate achieved outcomes. This should be developed by one case manager who navigates the system and coordinates the total requirements of the person’s current and future care and support needs, focusing on the move between hospital and home and outlining the necessary services. It should be flexible and responsive to a person’s changing needs over time.

### **Training**

Brain Injury Australia believes there is considerable unmet need for ABI-specific training - in both basic awareness and more specialised training; in the management of “challenging behaviours”, for example. A comprehensive national training programme needs to be devised and funded under any “national disability scheme”, with a particular emphasis on provision of appropriate services to ATSI and culturally and linguistically diverse communities.

#### ***“How should service providers be monitored and regulated with respect to quality, outcomes and cost effectiveness?”***

There are a number of reputable, independently audited, quality systems. These systems are readily adaptable and when combined with individual client feedback evaluation mechanisms can provide a comprehensive reporting and accountability process.

In addition, a consequence of introducing individualised funding will be control for the individual over their choice of service provider. Service providers will no longer have a monopoly and the “open market” environment will increase competitiveness and, consequently, standards.

#### ***“How would services be structured to increase the likelihood of participation in work and the community?”***

In a broad policy sense, a product of any service system should be demonstrated outcomes of community participation including engagement in the workforce. The underlying principle should be that a person with a disability who adds value to the community will in turn be valued by the community.

Three out of four people with an ABI will make a good *physical* recovery. In terms of barriers to employment, people with ABI may experience greater difficulty as result of their cognitive-behavioural disability than with questions of physical access to and mobility within the workplace. Impairments in memory and concentration, fatigue and “challenging behaviours” are common. The education of employers (and fellow employees) in ABI awareness is crucial as, for example, ABI is regularly confused with intellectual disability. Brain Injury Australia insists that the widespread lack of awareness and understanding of ABI is perhaps the greatest hindrance to community access. Therefore, education, awareness-raising and increased interaction with people with an ABI is necessary to combat current attitudes and ignorance. A commitment to such initiatives in any proposed “national disability scheme” is essential.

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- <sup>xii</sup> A distinction should be drawn between head injury and TBI. The former can include external injuries to the face and scalp and may or may not cause TBI.
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- <sup>xv</sup> Morrell et al. (1998)
- <sup>xvi</sup> Schofield et al. (2007)
- <sup>xvii</sup> Butler & Milner (2003). Loss of consciousness following an injury to the head can indicate that there has been an effect on the brain, although as discussed above, not all head injuries can properly be classified as an ABI/ TBI.
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<sup>xliv</sup> Access Economics (June 2009). *The cost of traumatic SCI and TBI in Australia*: 66.

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<sup>xlvi</sup> Clinicians in Queensland have identified that the lack of ABI beds and slow stream brain injury rehabilitation beds is causing significant “bed block” in the acute sector,  
**Publicly Funded inpatient beds for brain injured patients - 2006**

State	* Beds per Population	# Adjusted Queensland figures
Queensland	1 bed per 152,461 of state population 0.65 beds per 100,000 of state population	Currently 26 beds
South Australia (receives patients from NT)	1 bed per 55,071 of state population 1.82 beds per 100,000 of state population	Approx 72 beds
Western Australia	1 bed per 69,313 of state population 1.44 beds per 100,000 of state population	Approx 57 beds
New South Wales	1 bed per 141,129 of state population 0.71 beds per 100,000 of state population	Approx 28 beds (Note: relates solely to Traumatic Brain Injury patients).

Source: BIRU-PAH Benchmarking Report

\* Bed numbers and population statistics are current as at 30 June 2006. Beds refer to publicly funded ABI beds for individuals aged between 16-65 years, except where otherwise stated.

# Adjusted figures represent the number of ABI beds needed in Queensland to match that of the rate for the corresponding state.

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