Brain Injury Australia: Submission to the Australian Government’s National Mental Health and Disability Employment Strategy

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INTRODUCTION:

Acquired brain injury (ABI) refers to the multiple disabilities arising from any damage to the brain that occurs after birth. Common causes of ABI include accidents, stroke, infection, alcohol and other drug abuse and degenerative neurological disease. Traumatic Brain Injury (TBI) is an ABI caused by a traumatic event, from an external force to the brain such as a motor vehicle accident, a fall or a blow to the head.

ABI is common in Australia. In 2003, 432,700 people (2.2% of the population) had an ABI with “activity limitations” or “participation restrictions” (see Glossary, below) due to their disability:

- Almost 3 out of every 4 were aged less than 65 years.
- 160,000 had “severe or profound core activity limitations” (see Glossary).
- 2 out of every 3 were aged under 65 years, half of them between 15 and 34 years of age.
- 3 out of every 4 were men.

27,300 people with an ABI aged under 65 years experiencing “activity limitations” or “participation restrictions” said their ABI was the “main disabling condition” (see Glossary):

- 9 out of every 10 said their ABI was caused by accident or injury.
- More than 50% of them said the accident or injury occurred on a street, road or highway.
- 2 out of every 3 said that they acquired their brain injury when they were aged under 25 years of age.

National-level information about the incidence (new “cases” each year) of ABI is unreliable. Hospital admission data is compromised by the fact that not all people who suffer an ABI are hospitalized. It is estimated that 70%-85% of all TBIs fall into the mild category and while those injuries rarely require inpatient rehabilitation, between 10%-15% of people with mild TBI report physical complaints including headache, difficulty with attention and memory; and irritability, insomnia and sleeping difficulties. Furthermore, even given new statistical linkages between different hospital datasets, ABIs requiring multiple hospital admissions are susceptible to double-counting. Given these limitations in the incidence data, in 2004–05, there were 21,800 admissions to Australian hospitals for which a diagnosis associated with TBI was recorded as either the principal or an additional diagnosis. Approximately 6,000 were for young people aged 12-24. The rate of admissions was highest among men of aged between 15 and 24 years—almost 300 hospital stays per 100,000 people. Generally, men accounted for more than two-thirds (69%) of admissions. The heritage of research on the outcomes of TBI shows that roughly 1 in every 5 hospital admissions for TBI (above) will result in some permanent and/or profound disability. Even given the limitations, crucial to any understanding of the costs of ABI to individuals, families and communities is that its incidence is highest in young (mostly) men in the prime of life, coinciding with important events such as completing their secondary education, entering further study or employment and establishing their own families.

The consequences of an ABI can be profound, complex and multiple. The physical problems commonly reported by people with an ABI include headaches, fatigue, seizures, poor balance and coordination, visual and hearing disturbances, chronic pain, paralysis and epilepsy. Many people with an ABI experience cognitive problems, including poor memory and concentration, reduced ability to learn, plan and solve problems. Roughly two-thirds of
people with an ABI exhibit shifts in behaviour post-injury, including poor impulse control and disinhibition, aggressive verbal and physical tendencies. In that context the psychosocial-emotional problems consequent to ABI can be debilitating. A person who has experienced an ABI has a 80% likelihood of developing a diagnosable mental illness. (Conversely, people with psychiatric conditions are at risk of incurring a subsequent ABI.) The types of psychiatric disorders present after (or before) an ABI may include major depression, anxiety disorders, borderline and avoidant personality disorders, and bi-polar affective disorder. There are several types, or combinations, of disabilities that come under the heading of “Dual Diagnosis”, one of which is ABI and mental illness. ABI is often referred to as the “invisible disability” because its consequences, even if observable, are often not associated with disability generally nor ABI specifically. (This is especially the case with people with a mild or moderate ABI). The cognitive-psychological and psychiatric problems, while often the consequence of ABI, can also mask it. The presentation of ABI and mental illness can be very similar. Indeed, in some clients it is impossible to separate whether a presentation is due to ABI, or mental illness, or both. The local and international study evidence demonstrates that roughly one third of clients of a mental health service have an underlying ABI.

The Australian Bureau of Statistics’ 2003 Survey of Disability, Ageing and Carers provides information on need for assistance across 10 “life domains” - three core activities (mobility, self-care and communication) and seven “non-core activities”. The area with which people with an ABI most commonly required assistance was cognitive and emotional tasks. Over 100,000 people, or more than one-third of all people with an ABI aged under 65 years, reported needing help in this area. Compared with people with disability generally, people with ABI were more likely to need assistance with mobility, self-care, cognitive and emotional tasks, paperwork, transport, health care and meal preparation. Almost 30% of people with ABI aged under 65 years living in households needed help with at least one core activity, and 4% needed help with all three core activities. In comparison, 26% of people with disability generally needed help with at least one core activity, and 2% needed help in all three areas.

The international literature shows that ABI is 10 times more common and produces, on average, 3 times the level of disability as spinal cord injury.

The discussion paper that informs the Australian Government’s National Mental Health and Disability Employment Strategy records 2003 reporting from the Organisation for Economic Co-operation and Development (OECD), that Australia: ranked 13 out of 19 countries on the employment rate for all people with disability; had the lowest of 16 countries on the percentage of people on disability related benefit employed; had the “highest of 16 countries on the percentage of people receiving disability related benefit who were not engaged in formal work”; “in 2003, the unemployment rate for people with disability averaged 8.6 per cent compared to 5.0 per cent for people without disability” and “since 1993, the labour force participation rate of people with disability has fallen, while the rate for people without disability has risen. In 2003, 53.2 per cent of people with disability participated in the labour force compared to 80.6 per cent of people without disability.”

A 1999 Australian Institute of Health and Welfare analysis of open employment services for people with disabilities and support given directly to, or attributed to, individual clients (“direct support”) and other support (including general job search and travel) found that, while people with an intellectual/learning disability had the highest mean direct support per client at 68 hours, followed closely by people with an ABI (65 hours), when compared with 1996-97, the mean level of client support required had fallen for all disability groups except for people with an ABI.

Brain Injury Australia: Submission to National Mental Health And Disability Employment Strategy (June, 2008)
In 2002, Brain Injury Australia was commissioned by the then Department of Family and Community Services to conduct a study into ABI and employment. Its detailed analysis of data from the Australian Bureau of Statistics’ 1998 Survey of Disability, Ageing and Carers found that:

- Only 36.5% of people with an ABI were participating in the workforce (working or looking for work) compared to 53.2% of people with a disability generally, and 80.1% of people without a disability.
- People with an ABI had an unemployment rate of 18% compared to 11.5% for people with a disability generally, and 7.8% for people without a disability.
- 17% of people with an ABI reported that they were in full-time employment compared to 31% of all people with a disability.
- Only 30% of people with an ABI were in any employment compared to 47% of all people with a disability.
- 48% of people with an ABI were permanently unable to work compared to 27% of all people with a disability.
- 86% of people with an ABI reported having an employment restriction compared to 70% of all people with a disability.
- 9% of people with an ABI reported a need for ongoing assistance and supervision in employment compared to 5% of all people with a disability.
- 12% people with an ABI reported needing other special employer arrangements such as building or fittings modification, training and different duties compared to 9% of all people with a disability.
- While there was considerable growth in the total number of people receiving disability employment services between 1998 to 2001 - from 67,174 to 91,864 - there was relatively little movement in the number of people with an ABI receiving services – from 3,248 to 3,975 – representing a 0.1% increase in their proportion of to the total number of people receiving disability employment service (the study estimated the total “potential population” of people with an ABI capable of some participation in the workforce at 74,800). During the same period the participation rate for people with a physical disability increased from 29.4% to 29.7% and for people with a psychiatric disability, from 19.9% to 21.6%.

The most recent analysis of the Commonwealth State/Territory Disability Agreement’s National Minimum Data Set - specifically the utilisation of employment supports by people with an ABI - tends to confirm these 2002 findings; “people with an ABI were less likely than service users generally to access disability employment services”. Only 16.3% of people with an ABI accessed open employment services, compared with 21.9% of all service users, 7% of people with an ABI accessed supported employment services, compared with 9.3% of all service users. Overall 24.1% of people with an ABI accessed employment services, compared with 32.3% of all service users.\(^6\)
Brain Injury Australia (BIA) is the national peak ABI advocacy organization representing, through its State and Territory member organizations and network relationships, the needs and interests of people with an ABI, their families and carers. A major component of BIA’s role is:

- 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 organizations.

“What is the issue or problem that you think can make it more difficult for a person with disability and/or mental illness to find and keep work and to develop their career?”

The relatively low rates of participation of people with an ABI in finding and keeping employment have their explanation in barriers some of which are individual, some systemic. And they are: likely to be happening at multiple points in the pathway to employment; having a differential impact, depending on a person’s social and personal circumstances, age, and the type and cause of their ABI and not well-articulated for people whose ABI is caused by alcohol, other drugs, illness, or particularly if they are older. But Brain Injury Australia strongly believes that the means to the overcoming of barriers to employment for people with an ABI begins with building awareness of ABI throughout the community.

**INDIVIDUAL BARRIERS:**

Brain Injury Australia’s 2002 study into ABI and employment included detailed individual interviews and focus groups conducted with over 50 people with an ABI (as well as family members and carers). They represented men and women aged 20 to over 60 of different cultural, educational and socio-economic backgrounds and types of ABI.

Some of the individual barriers to employment and access to employment support found were:

- **Many people with an ABI (especially in the moderate or mild categories) do not see themselves as having a disability** and, thus, as candidates for the disability employment system. The study uncovered a pattern of people with an ABI moving in and out of the general employment market seeking to use their abilities, often self-initiating job applications, and often finding their new incapacities irreconcilable with the kind of work they undertook before their ABI. The costs of these initial failures – in damage to self-confidence and, importantly, in an entrenched reluctance to re-engage with the job market are very considerable.7
Generally, people with a disability are experts in their own needs. They will understand the impact of their disability on work performance and any workplace adjustments they may need at interview, while training or on the job. However, many people with an ABI do not readily disclose their disability.

“When I was first applying for jobs I put [my having an ABI] in, and then I stopped doing it, because I found that you never got interviews. And then I started leaving it out and all of a sudden I got interviews… then [at interview] I got looked at like a fire-breathing monster alien, but it was very interesting the difference, putting it in, or leaving it out....”

For some people with an ABI their non-disclosure may not be a critical issue, as their disability - due to aspects of their appearance or speech - may become potentially identifiable. Brain Injury Australia argues that disclosure is almost always a two-way street, that: as much as government agencies and employment services providers may expect that is the person’s responsibility to acknowledge their ABI, there may be a host of reasons for secrecy – the age at which a person acquired their brain injury, its causes, its consequences. And government agencies and employment services have at least an equal responsibility to make their practices – and their staff – disability-aware enough for the client environment to be conducive to disclosure.

However, often a person’s ABI will not be readily apparent in an interview but may become apparent later on the job. In this case appropriate disclosure strategies may be vital to ensure that the client receives the training and support they need to make the work placement succeed.

“When your disability is invisible, you can sometimes bluff your way into jobs [without the employer realising that you have an ABI]”... “I think a lot of people bluff their way into jobs, and then screw up... the invisible always becomes visible eventually.”

“I had a client who was very bright, but after his brain injury he had little insight into his deficits. He could go to interviews, present well, get the job, then lose it soon after. Why? For example, cleaning his feet at his desk, then touching other employee’s keyboards. For example, changing the data entered into the business’ computer, because he believed the original figures weren’t accurate. In the first instance, he did what he needed to do, and could not see why others were complaining. In the second, he believed he did the ‘right thing’, but he had not understood the overall task or the implications of what he’d done. He was smart and thoughtful enough to try to do a better job, but not insightful enough to realize that his actions had serious negative consequences for other parts of the business. He had a great work placement case manager but we could not keep him employed long enough to find a way to overcome his lack of insight.”

Where a person feels comfortable to disclose their ABI they may not necessarily have a high awareness of areas in their post-injury capacities that require additional support for finding and keeping employment. Unrealistic employment goals and a lack of insight are some of the characteristics of people with ABI often described by service
providers and more generally in the research literature. Some people with an ABI are unable to recognise the behaviours which are not acceptable in workplaces. The majority of people with an ABI who formed Brain Injury Australia’s 2002 study focus groups felt work was a vehicle to re-establishing their lives, but that the job needed to be relevant to their sense of self - future and past. That is, the right job was their priority - not any job.

“I’m a university graduate. The service provider thought I would be happy putting tops on pens, but that would just demoralise me. It’s a job for someone who is developmentally delayed. They just don’t take account of pre-injury work history.”

“I have hemiplegia [paralysis of one side of the body] resulting from my ABI. However due to my capabilities and level of independence I am not suited for the simplistic sheltered workshop-type environment offered by disability employment agencies, and ‘normal’ job-seeking agencies don’t know what to do with me either. We need disability job agencies that focus on our abilities and try to place us in ‘normal’ work places wherever possible.”

- Disability employment services were seen as the “last resort”, particularly employment services where groups of people with different types of acquired and developmental disabilities were working together. This was because of the association with people with other disabilities – especially intellectual disability, with which ABI is regularly confused - and the perceptions by people with an ABI of the low expectations attributed to workers with disabilities in these settings. This failure to accept the existing disability employment service options could sometimes be interpreted as people with an ABI lacking insight, being unrealistic. Perhaps so, in certain cases, but from a client-of-a-service’s perspective their experience remains valid.

- Many people with an ABI do not see disability employment services as relevant to them and therefore do not present.

- Many people with an ABI do not know about disability employment services and therefore do not inquire.

**SYSTEMIC BARRIERS:**

“Every Australian should have an opportunity to be a full participant in the life of the nation. Unfortunately, too many Australians remain locked out of the benefits of work, education, community engagement and access to basic services. This social exclusion is a significant barrier to sustained prosperity and restricts Australia’s future economic growth. Promoting social inclusion requires a new way of governing. Australia must rethink how policy and programs across portfolios and levels of government can work together to combat economic and social disadvantage.”

*Brain Injury Australia: Submission to National Mental Health And Disability Employment Strategy (June, 2008)*
Brain Injury Australia welcomes the Australian Government’s commitment to social inclusion, led by the Prime Minister, the Deputy Prime Minister and the newly established Australian Social Inclusion Board. Brain Injury Australia’s constituency – described in the Introduction, above – includes some tens of thousands of the most socially excluded Australians. It should be noted that people with an ABI are drawn from the same populations as those at the greatest risk of any injury and with generally lower workforce participation rates – of low socio-economic status: from poor housing; large family size; histories of abuse and neglect; marital breakdown; parental drug or alcohol abuse and substance abuse; mental illness and poor levels of education.9

Brain Injury Australia urges the Australian Government, in its pursuit of a social inclusion agenda for policy, not to underestimate the genuinely social in social inclusion. Governments could learn from the results of the longest long-term study ever conducted in Australia of the outcomes of ABI – a 20-26 year follow-up of 100 men with Traumatic Brain Injury admitted to Sydney’s Lidcombe Hospital between 1976 and 1981. Apart from the fact their needs for support were ongoing so long post-injury - 85% had used at least one service in the preceding twelve months – their greatest unmet need (for 73% of them) was for some form of “social participation activities”10. For many of the people with an ABI who are the intended targets of the Australian Government’s National Mental Health and Disability Employment Strategy, their first engagement with the world of work may be their very first engagement with the wider world per se. Which is why the nature of that first engagement with the pathways to employment – how disability-inclusive and how ABI-aware it is – is absolutely crucial. Because failure, because of systemic barriers, risks permanent exclusion.

An example. 75% of traumatic brain injuries in New South Wales are caused by motor vehicle accidents. 70% of those injuries happen to men, 40% to men aged between 17 and 25. And while traumatic brain injuries represent less than 2% of claims made on the state’s Compulsory Third Party (CTP) scheme, they account for half of the Motor Accidents Authority of New South Wales’ large claims and nearly one-fifth of the scheme’s total cost. Their average cost is roughly $1 million. In partnership with Rotary’s Youth Driver Awareness (RYDA) program, Brain Injury Australia’s New South Wales member organization - the Brain Injury Association of New South Wales - has established a 40-member Speakers’ Bureau; of people with a traumatic brain injury who share their experience of road trauma with high school students. Over 50,000 students have participated in RYDA since its inception in 2000. The benefits of such a program are manifold. Firstly, the Bureau caters to the enormous community enthusiasm for road safety information. Secondly, the Bureau satisfies Rotary’s objectives of community benefit and aids the socially disadvantaged. Thirdly, low community awareness about Acquired Brain Injury is raised. Fourthly, injury prevention moneys are available to the Bureau to match community interest in road safety. Fourthly, and most importantly for the Association’s mission, the benefits to the speakers of sharing their experience of ABI, of simply being heard, are immense. A survey conducted of speakers involved in a similar program - Sydney’s Westmead Hospital “Think Twice” - found that while none were working or studying at commencement, 60% had left the program after 18 months to commence full or part-time work or study. For many of the speakers, their involvement in the program represented their first social venture since their ABI.

The Australian Institute of Health and Welfare’s (AIHW) 2007 report into “Current and Future Demand for Specialist Disability Services” found that, despite an increase between 1998 and 2003 of 25,300 people aged 15–64 years with severe or profound core activity limitations who were not in the labour force, unmet demand for Commonwealth State/Territory Disability

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Agreement (CSTDA)-funded Community Access Services - providing opportunities for people with a disability to enhance their social independence by accessing services and facilities generally available in the community (like the “speakers” programs, above) – had actually decreased by around 4,500 during the same period. Though the apparent decrease in demand may be partly due to the disciplines of “welfare-to-work”, the AIHW warns that “in coming years, demand for community access services may be expected to increase, due to growth of the CSTDA target population.” Moreover, “among people aged 0–64 years, the broad disability groups with the highest projected growth rates are physical/diverse disability (6%) and Acquired Brain Injury (5%)”. Brain Injury Australia is convinced that CSTDA-funded Community Access Services can act as a stepping stone to wider social engagement for people with an ABI, specifically into workforce participation.

**Recommendation One:**

Brain Injury Australia recommends that, in keeping with both the Australian Government’s whole-of-government commitment to a social inclusion agenda and the projected growth rates in the number of people with an Acquired Brain Injury in the Commonwealth State/Territory Disability Agreement’s (CSTDA) target population, the Department of Families, Housing, Community Services and Indigenous Affairs, enhances funding for Community Access Services in all future iterations of the CSTDA.

**1. INFORMATION:**

“I remember one anecdote from a man with an ABI who went to Centrelink. They asked him to fill in a form. He said that he couldn’t. And this was true. His vision was fine, but his cognitive problem was such that he could not interpret forms. And he could not explain himself well. The staff member took him to be ‘taking the piss’ and sent him out.”

The report of the Human Rights and Equal Opportunity Commission’s 2005 National Inquiry into Employment and Disability – “WORKabilityII: Solutions – People with Disability in the Open Workplace” found an absence of easily accessible and comprehensive information and advice that assists in decision-making and responds to the ongoing needs of people with a disability. This directly coincides with the experience of people with an ABI who participated in Brain Injury Australia’s 2002 study into employment. Generally, there is insufficient disability-accessible information throughout the employment services system for and about people with an ABI: in particular, available to public sector and private employers, general practitioners, tertiary education providers, and community counselling and support services. These are the groups that are potential referral sources for employment and who are likely to be in ongoing contact with people with an ABI and their families, many of whom are active in trying to promote workforce participation.
Recommendation Two:
Brain Injury Australia recommends that the Department of Families, Housing, Community Services and Indigenous Affairs engages Brain Injury Australia – and its State and Territory member organisations – in the production and dissemination of a range of forms and publications appropriate and easily accessible for and about people with an Acquired Brain Injury.

2. AWARENESS:

“I work with a person in a wheelchair. With everything she does everyone says ‘Isn’t she great!’ With my ABI, I do something and everyone says, ‘I knew you were lying’.”

“I appear OK, so people think, ‘What’s wrong with you?’”

Brain Injury Australia’s daily experience is of the poor community understanding of ABI and it manifests at every point of the employment services system. The impact of ignorance, fear and bias from government agencies, service providers and potential employers typified the experiences of people with an ABI who participated in Brain Injury Australia’s 2002 study into employment. It seems nothing has changed since.

Brain Injury Australia is also aware that Centrelink is regularly used as a punching bag for consultations like this – because it’s often at the front line of Australian Government social policy reform. Brain Injury Australia is equally aware that Centrelink staff are ultimately entirely dependent on what an individual client and/or a referring service tells them. As part of the consultations that informed Brain Injury Australia’s 2002 study into employment Centrelink staff, while feeling disadvantaged by an inadequate level of preparation for dealing with people with ABI, also stressed their role did not include specialist quasi-diagnostic assessment – if, say, a person with an ABI arrived at Centrelink without evidence of previous assessments and with no preparedness to discuss their disability.

“One of the problems in some Job Capacity Assessments is that people with ABI do too well. There are domains in which they perform better than, say, people with an Intellectual Disability, and so their overall scores go up and they look good. But there are domains on which they can be terrible. And one problem on one domain can make employment pursuits impossible.”

This is the role intended to be fulfilled by Job Capacity Assessors. In its submission to the Department of Human Services review of the Job Capacity Assessment Program, Brain Injury Australia forwarded evidence: of people with an ABI who are often told by JCAs “you don’t seem to have any obvious disabilities so there’s no reason why you shouldn’t be working 30 or more hours per week” or from conversations Brain Injury Australia has had with JCAs: one, a qualified
psychologist, already knew where to begin an assessment of a client with an ABI - "...give them an IQ test". Brain Injury Australia is regularly made aware of inaccurate Job Capacity Assessments that result in either inappropriate referrals of people with an ABI to Job Network and Disability Employment Network providers (people with ABI are consistently being assessed at levels lower than their actual support needs) or the denial of a Disability Support Pension in favour of Newstart Allowance, with the associated mutual obligation requirements. The costs of either – in failure at a first attempt at workforce participation or in compliance breaches – can result, again, in permanent disengagement from workforce participation.

"Some years ago I was involved in ABI training for Centrelink. Everyone in the room was management. There were no front-line assessors. Not one. So management went back to their desks, and clients continued to bump into untrained assessors."

Recommendation Three:

Brain Injury Australia recommends that the Departments of Families, Housing, Community Services and Indigenous Affairs, Human Services and Education, Employment and Workplace Relations engage Brain Injury Australia – and its State and Territory member organisations – in the provision and/or procurement of training in Acquired Brain Injury for their agencies’ staff and management.

3. "WELFARE TO WORK”:

Brain Injury Australia’s general concerns about the “Welfare to Work” reforms of the previous government remain unchanged, namely:

- the fear of a person with an ABI losing their Disability Support Pension acts as a direct disincentive to looking for work;
- people with ABI assessed as being able to work between 15-29 hours per week will no longer be eligible for the Disability Support Pension, but will instead be diverted to Newstart Allowance;
- in addition to a lower base rate, Newstart Allowance recipients are subject to harsher income and onerous activity tests. This not only makes it harder for people to meet their non-optional costs of disability, making it harder in turn for them to find and maintain employment but people with memory and cognitive impairment the consequence of their ABI – especially where those “invisible” aspects of their disability remain unrecognized, undetected - have difficulty remembering, or understanding, the activity tests and reporting requirements, and may unintentionally place themselves in breach of compliance and
- the reform’s emphasis remains on placement in any job. Given the life circumstances (e.g. their employment background) in which many people acquire their brain injury, this devalues the individual’s place in setting their own goals and aligning work with their values, skills, and aspirations.
Recommendation Four:
Brain Injury Australia recommends that the Departments of Families, Housing, Community Services and Indigenous Affairs, Human Services and Education, Employment and Workplace Relations review the difference – as a (dis)incentive to workforce participation – between the Disability Support Pension and Newstart Allowance and reform the activity test requirements of the latter to accommodate those Australians with a cognitive disability.

4. EMPLOYMENT SERVICES:

“Physical and intellectual disabilities are easier for employers to understand and decide on. People with an Acquired Brain Injury are just harder.”

Of the 230 disability employment assistance services surveyed as part of Brain Injury Australia’s 2002 study into ABI and employment, more than two out of every three services were supporting small numbers of people with an ABI, typically one to five people (for a total of 732). While there was an apparent willingness to support people with ABI implicit in the number and nature of comments received from disability employment assistance services, there was also evidence (like the comments, above and below) that job-seekers with an ABI were perceived as difficult and challenging by service providers who may be less than willing to “take them on” – employment services generally, disability employment specialists included were choosing potential job-seekers where there was a higher likelihood of getting employment outcomes.

“It was felt that people with an ABI would not be described by employment services providers as highly likely to achieve “outcomes” when support intensity was rationed, time-limited and if it did not allow for multiple work trials and job placements. The 2002 study found increasing numbers of disability employment services alluding to a “competition between disability groups” whereby – with a limited pool of positions suitable for people with disabilities in the open employment market - the “traditional” disabilities, that is physical or intellectual disabilities, were preferred as being easier to place and easier to support. It is generally recognised that many people with an ABI need longer and sustained assistance to gain and then maintain employment. Brain Injury Australia’s 2002 survey found that employment services perceived people with an ABI as often requiring the most intensive long-term support and as having poor sustained employment outcomes in the absence of support. Moreover, the survey found that there are not enough employment services support staff with specific training in ABI - who can work flexibly in the workplace with the individual, co-workers and the employer in relation to workplace and job-design and who can support co-workers and employers.”
A client with an ABI also requires staff skills and knowledge to implement the features of effective employment support, such as:

- how to negotiate **several attempts to find suitable employment** - including supporting preparatory work training and trialing at different sites, for prolonged times if needed;
- ensuring **flexibility of job design** - this includes the number and schedule of hours; a slower rather than a faster pace; having opportunities for breaks and more structure rather than less;
- ensuring ongoing support for as long as required - a minimum of 12 months support for many people was consistently reported in Brain Injury Australia's 2002 survey\(^6\). This includes staff being available to go back into an organisation to provide support to employers, co-workers, and/or people with acquired brain injury at a point of change or an emerging difficulty;
- knowing how to give helpful feedback to people with an ABI - and to coach supervisors about how to provide feedback;
- Maintaining productivity - this could mean support workers being in the workplace until the individual has adapted to the demands of the work; that is, the support worker works alongside the person with an ABI while training is completed; and
- responding to whether people with an ABI wish to disclose their disability and to whom - this means that one element for effective employment support may be support that is not revealed in the workplace.

Brain Injury Australia notes that the **vast majority of the open employment services membership** of the Association of Competitive Employment (ACE) - the peak body for Australia's Disability Employment Network (DEN) – are either generalist in nature (57%) or **specialists in intellectual disability** (23%). It has been Brain Injury Australia’s experience of generalist services that approaches suitable for people with an Intellectual Disability predominate.

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“People with an Intellectual Disability need support till they have learned the job. But then they’re OK. Acquired Brain Injury often needs ongoing support.”
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“The [low] rate of pay is often better accepted by people with an Intellectual Disability: People with Acquired Brain Injury have higher job aspirations.” (Disability Employment Network service provider)
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Historically, the **service response to people with an ABI has focused on maximising recovery from their injury during the acute and rehabilitation stages.** Few services have developed particular expertise around supporting the disabilities associated with ABI in the context of community living, including employment. Not surprisingly, there is a limited understanding of ABI by staff in disability employment services, although many of them have expertise in other areas of disability.

Brain Injury Australia’s 2002 study found that employment services staff are ostensibly willing but not proactive in their efforts to respond to the specific needs of people with an ABI. So, if a person with an ABI does present, services are willing to respond but ordinarily according to their existing service paradigm - their responses are in terms of existing practices that reflect the needs
of other disability groups. Brain Injury Australia believes that this raises a much larger question than the importance of employment services individualizing their responses. Alongside the general lack of awareness of ABI is a lack of advertising, outreach and service design strategies for people with an ABI which creates specific access barriers. In principle, these are almost identical to the barriers experienced by people, for example, from indigenous and culturally and linguistically diverse backgrounds accessing generalised services. Overall, the disability employment assistance services surveyed in 2002 noted that people with an ABI: were generally poorly understood in their sector; experienced little public acceptance; had a lower profile in the disability employment assistance service system; little systemic support and less “political patronage”.

**Recommendation Five:**

Brain Injury Australia recommends that, given the size and nature – specifically, its susceptibility to entrenched disengagement from workforce participation – of the population of people with an Acquired Brain Injury, and its predicted increase, that the Departments of Families, Housing, Community Services and Indigenous Affairs and Education, Employment and Workplace Relations foster and fund specialist Acquired Brain Injury employment support services.

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5. **ACQUIRED BRAIN INJURY-SPECIFIC BARRIERS:**

It was the almost universal view of people with an ABI, their carers and family members who took part in the focus groups that informed Brain Injury Australia’s 2002 study into ABI and employment that, while workforce participation was both worthwhile and desirable, it was still only a part of “whole of life” supports – including, for example, support for a person who is in conflict with family members, or is losing friends/ social supports, has an alcohol and/or other drug problem, has little pre-injury work experience, has mental health problems, and/or is struggling to cope with their cognitive impairments. Moreover, lack of appropriate accommodation was identified as a key barrier to employment for people with an ABI by specialist advocacy services.

There was persistent experience of: disjointed transition from acute care to rehabilitation to community support leading to potential employment; a lack of service and support networks especially in rural and remote communities; and a lack of early identification and intervention because of poor transition from the education system into employment services. There was also poor awareness by professionals in non-vocational settings about the availability of open and supported employment services for people with an ABI and a general lack of ongoing support, monitoring and case management. **It is precisely the work of Brain Injury Australia – and of its State and Territory member organisations – in systemic, individual and self-advocacy, in case management and in information and referral that fills these gaps for people with an ABI as they re-form their lives and re-join the world of work.**
Recommendation Six:

Brain Injury Australia recommends that the Department of Families, Housing, Community Services and Indigenous Affairs, as part of its ongoing review of the National Disability Advocacy Program (NDAP), fund Brain Injury Australia – through its State and Territory member organisations – to provide specialist advocacy services in all jurisdictions to people with an Acquired Brain Injury.

“I work with some clients with an Acquired Brain Injury who want to work, are actively trying to gain employment, but cannot secure a job. One client has been working with disability employment agencies for many years. She has considerable skills to offer the workforce and has been to many interviews, but unfortunately she has not been offered employment in recent years. She has formed the impression that employers discriminate against her because she has epilepsy. One job placement that she did commence about 2 years ago failed as there was insufficient on-the-job training and support for her. What would have worked better was for her to have a mentor on the job and for her employer to be provided with information regarding her disability and compensatory strategies that would assist her perform the duties (e.g., having written instructions and cue cards to aid memory, less pressure to take phone messages quickly, having larger print on forms making them easier to read and enter notation).”

“I have a client with an Acquired Brain Injury who is able to gain employment but often cannot hold down a job. He has worked in many different fields over the years and has a range of valuable skills and experience. Unfortunately, because he has poor impulse control and low frustration tolerance, he becomes frustrated and angry when the employer or colleagues do not do what he expects. This client also has difficulty pacing himself, and will initially take on too much, get stressed, and then not function optimally. He also would benefit from a mentor or appropriate supervision and support such that he and his employer could work on a reasonable work plan, manage his level of duties and proactively address difficulties so as to prevent them from becoming major issues that jeopardise his job.”

Workplace modifications generally fall into two groups - formal adjustments made by the employer and informal supports in the workplace or affecting the workplace. There is limited evidence for what number, and in which combination, such adjustments can determine employment outcomes for people with an ABI. But for people with psychiatric disabilities there has been a significant relationship reported between job retention and the number of accommodations - with five or more accommodations resulting in twice the average job tenure. The two most significant accommodations were employer training and support and assistance at the worksite; that is, factors not necessarily related to the individual characteristics of the employee.

There are a range of barriers to effective workforce participation very specific to people with experience of ABI. They include:

- **Working hours:** some employers will expect all employees to be able to work for preset periods, an 8-hour day for example. This is often incompatible with the fatiguability that is a common consequence of ABI, along with the increased demands for people with...
cognitive impairment processing information and concentrating for extended periods of time.

- **Complex working environments:** people with cognitive impairment often find complex workplaces, with an array of competing activity and noise difficult, and tiring, to concentrate in.

- **Communication:** for example, short-term memory loss is the most common consequence of ABI, necessitating adjustments to work practices where regular reminders and repeats of instructions need to be the norm.

- **Lack of tailored, individualised support and mentoring:** as a consequence of the demands listed above, many people with an ABI need regular support and assistance in structuring their work tasks and work day.

- **Limited direct understanding of the diversity of the impacts of ABI:** some people with an ABI may incur significant physical disability, others experience epilepsy, vision impairment etc.

Information resources specifically written for employers and fellow employees of people with an ABI are available, and should be more widely publicised. Wodonga TAFE and Aware Industries produced “Work Talk – Effective Workplace Communication with Employees with Acquired Brain Injury” in 2006

“What is the goal or goals that you would like the Strategy to achieve —these can be aspirational and high level, but should also be within the Strategy’s Terms of Reference?”

a) Because the baseline of general community awareness about ABI is so low, Brain Injury Australia considers any “achievement” against each of the recommendations contained in this submission to be a “goal”.

It is Brain Injury Australia’s view that Australian governments still fail to come to grips with either the challenge – or the community costs – associated with ABI. Unlike most other disabilities, it occurs in the prime of life – roughly half of all Traumatic Brain Injuries occur at age 22 or younger – often coinciding with key life events such as the completion of secondary education and/or entrance into further study or employment.

However, there is a paucity of local - and international – studies that point to what factors are centrally at play in post-ABI employment outcomes, so that government policy settings are correctly set and any interventions targeted. A recent Australian review of 85 separate studies concluded the following (which are important to read in the light of the population characteristics of people with an ABI detailed in the Introduction):

- **older adults were generally found to experience less favourable employment outcomes than younger adults,** “although most studies did not specify the age group in which the likelihood of returning to work decreases”;
- individuals with higher qualifications (executive or skilled professions versus unskilled professions) before their injury were more likely to return to competitive employment;
- pre-injury SES [socio-economic status] variables were stronger predictors of long-term vocational level and stability, than other demographic and injury-related variables (severity etc.);
- that individuals who receive specialized rehabilitation and vocational support “make greater functional gains and adjustment to their injury and, thus, these services are effective in assisting people with an ABI’s return to work”;
- individuals with a TBI who have been away from work due to various circumstances need to be motivated to return to the labour market (“for individuals with a TBI, the direct effects of their injury may lead to a loss of motivation and drive - i.e., adynamia. Additionally, low motivation can arise from individuals’ psychological reactions to the effects of their injury which include depression, anxiety and loss of self-confidence...rehabilitation programs also need to target deficits in motivation and emotional disturbance”;
- the need for employers and co-workers to be willing to facilitate the implementation of supported employment, which might include modified duties, adaptation of equipment and the physical environment and close communication with an employment specialist....“Additionally, employers and colleagues require education and training regarding TBI and an understanding of the individual’s strengths, deficits and strategies for compensating for, or accommodating his or her deficits” and
- clients without a history of pre-injury substance abuse were more than eight times as likely to gain employment following TBI compared to clients with a history of pre-injury substance abuse18.

b) Brain Injury Australia believes that ambit goal-setting (for example, that x many more people with an ABI are in permanent employment by x date) is meaningless unless it’s informed by some knowledge of what’s working for people with an ABI in Australia’s employment services regime, and what’s not. Brain Injury Australia is unaware of any longitudinal study – that might test the conclusions, above - of employment outcomes for people with an ABI. Australian Government agencies should fund – with Brain Injury Australia’s aegis, and guidance – such a study.

c) The Australian Government is rightly interested in prevention measures for long-term unemployment. Taking into account the relatively high level and multiplicity and complexity of their needs with their relatively low rates of workforce participation, any opportunity that can be offered to people with an ABI to identify themselves for appropriate supports and referrals (to a Job Capacity Account, for instance) should be seized. Because the costs of not doing so should be viewed by governments as prohibitive. Thus, Brain Injury Australia believes that the beginning – and end – of goal-setting is measurement and, thus, the data collected. Any attempts at “top down” awareness-raising via the kinds of evidence-based arguments contained in submissions like this are hamstrung while “bottom up” data collection resists simply including, say, questions about disability in client information.
Recommendation Seven:
Brain Injury Australia recommends that the Departments of Families, Housing, Community Services and Indigenous Affairs, Human Services and Education, Employment and Workplace Relations directs its agencies to amend client data collection to include information by disability type generally, and about Acquired Brain Injury specifically.

Recommendation Eight:
Brain Injury Australia recommends that the Departments of Families, Housing, Community Services and Indigenous Affairs, Human Services and Education, Employment and Workplace Relations work with counterpart agencies – in, for example, health and corrective services - in each Australian State and Territory to improve data linkages for the purposes of collecting information about employment outcomes for people with an Acquired Brain Injury.

d) Where clients of employment services choose not to nominate their disability on a form or in an interview, this submission has referred repeatedly to reasons for the potential reluctance of people to disclose their ABI. Brain Injury Australia believes that making available basic awareness training in ABI to staff of government (and non-government) employment services will both create a service environment more amenable to disclosure of disability generally and enable front-line staff to detect an ABI when it is undeclared.

e) In an analysis of 38 dismissals from supported employment for people with a TBI, researchers found the reasons to be less related to the adequacy of the individual’s work skills, than to questions of inappropriate interpersonal and social behaviour. These included poor attendance, loss of motivation, inflexibility to changing work demands, decreased frustration management, anger, boredom, isolation and overwhelming anxiety and psychological distress. The analysis also found that most separations occurred in the first six months. The analysis did not examine the pathways to employment, nor the employers’ prior knowledge about the employee supports that might be necessary, nor what formal or informal adjustments the workplace had made to include a worker with an ABI. One clear goal that Brain Injury Australia can set is a reduction in both workplace dismissals and participation failures. One royal road to both of these is universal training in ABI awareness for all staff of employment services – government and non-government – which Brain Injury Australia can either provide or procure, combined with the implementation of ABI-appropriate services and support pre-employment and within workplaces.

“Is there anything else you would like to say about this proposal that is not covered under any of the previous headings?”

Brain Injury Australia is not aware of data indicating how many of the long-term unemployed are ex-prisoners or detainees of juvenile justice but believes any time in detention may be a risk.
factor for low workforce participation and knows that people with an ABI are radically over-
represented in Australia’s prisons. A 2003-04 survey of 200 New South Wales inmates found that
82% had experience of Traumatic Brain Injury (TBI), with 65% reporting a loss of
consciousness and, of those, 52% said they had ongoing effects (headaches, memory
loss, personality or behavioural change, anxiety or depression etc.) and 22% had
sustained four or more TBIs. These kinds of prevalence rates have been broadly replicated by
similar studies conducted by the NSW’s Department of Juvenile Justice, its Corrections Health
Service, the Centre for Health Research in Criminal Justice and Victoria’s Department of Justice.
Overall, somewhere between 40 and 60 per cent of people in custody in NSW and Victoria report
ABI. And these local survey results conform to results from overseas. Two US studies of death
row inmates found that 75% had a history of “brain damage” and 100% had a history of TBI.
Another study of prisoners in US county jails found that 87% of inmates had a TBI.

The 2003 Young People in Custody Health Survey, conducted by the New South Wales
Department of Juvenile Justice, found that 40% of young men had sustained an ABI resulting
in significant loss of consciousness. Most ABIs were the result of being struck by an
object or person during fights (63%). Memory loss (19%) and poor concentration (18%)
were the most common unresolved side-effects from reported ABI by young men.30 (Again,
it should be noted that the highest age-standardised prevalence of ABI in the general population
is in the 12-24 age group.)

But Brain Injury Australia is aware of only two jurisdictions - South Australia and the Australian
Capital Territory – that screen prisoners for a history of ABI at reception. Brain Injury Australia is
also unaware of any jurisdiction that screens detainees in juvenile justice prisoners for a history of
ABI at reception.

Recommendation Nine:

Brain Injury Australia recommends that the Australian Government urges, via the
Corrective Services Ministers' Conference (as well as equivalent meetings of State and
Territory ministers for juvenile justice), States’ and Territories’ departments of
corrections and juvenile justice to include the screening and identification of Acquired
Brain Injury in detainees at reception.

The Australian Institute of Health and Welfare’s 2007 report into prisoner health noted that “there
is no routine injury surveillance within Australian correctional systems. Jurisdictions report rates of
‘prisoner on prisoner’ and ‘prisoner on staff’ assaults as part of the annual Report on Government
Services published by the Productivity Commission. However, this is simply a tally of the number
of ‘Governor’s Reports’, is administrative in nature, lacks detail, is likely to underreport injury, and
does not aim to serve any public health purpose.”21

This is in spite of the fact that in New South Wales prisons, for example, assaults are the
second most common injury treated in the prison clinics.22 Whether a prisoner brings their
ABI with them into prison or acquires one while there, the potential consequences – in cognitive
function, in changed behaviour etc. (detailed in the Introduction) while detained or post-release -
should be well known, as should be the increased risk both of further ABIs and, thus, the potential
for re-offending.
Recommendation Ten:

Brain Injury Australia recommends that, as part of a whole-of-government approach to the prevention of long-term unemployment, the Australian Government urges, via the Corrective Services Ministers' Conference (as well as equivalent meetings of State and Territory ministers for juvenile justice), States’ and Territories’ departments of corrections and juvenile justice to improve surveillance, recording and reporting of Acquired Brain Injury among detainees.

While studies have consistently found high levels of ABI among prisoner populations, they are equivocal on a causal link between ABI, the personality and behavioural results of ABI and subsequent offending behaviour; whether the ABI itself is the cause of offending behaviour or whether the life circumstances of offenders who subsequently report ABI are perhaps criminogenic. What is clear is that prisoners and the kinds of people at risk of any injury have a lot in common – they tend to be poorer, they tend to have lower levels of education, they tend to have histories of mental illness, alcohol or substance abuse. (And they tend to be indigenous: the imprisonment rate for Aboriginal and Torres Strait Islander people is currently 13 times that of the rest of the population. It should be noted that the jurisdiction with the highest age-standardised prevalence of ABI also has the greatest proportion of its population identifying as Indigenous – the Northern Territory). And they tend to be men (93% of prisoners, around 75% of people with an ABI.)

Whatever the nature of the relationship between ABI and criminal activity, re-offending rates are generally high. The most recent Australian Bureau of Statistics National Prisoner Census found that 57% of prisoners in custody at 30 June 2007 had served a sentence in an adult prison prior to the current episode. Another survey of New South Wales prisoners found that 44% had returned after two years, and the rate was even higher for those convicted of assault or robbery.

While Brain Injury Australia does not believe that all roads from an undiagnosed, undeclared or unchecked ABI necessarily lead to prison or that a prison sentence inexorably leads to long-term unemployment, there is no substitute for correct identification, early intervention and better-targetted – and better-funded – services and support for detainees with an ABI as well as pre-release and post-release programs for prisoners in general, enabling workforce participation. Moreover, the appropriate care, support and management of people with an ABI in contact with the criminal justice system is not only a core responsibility of Australia’s departments of attorneys-general, corrections and juvenile justice - in recognition of the equal rights of people with disabilities - but also potentially an exercise in crime prevention.

Recommendation Eleven:

Brain Injury Australia recommends that, as part of a whole-of-government approach to the prevention of homelessness, the Australian Government, via the Corrective Services Ministers’ Conference (as well as equivalent meetings of State and Territory ministers for juvenile justice), directs States’ and Territories’ departments of corrections, juvenile justice, health and disability to provide appropriate levels of service and support to detainees with an Acquired Brain Injury.
GLOSSARY:

**activity limitations**
Activity limitations are “difficulties an individual may have in executing activities” such as learning to read (Australian Bureau of Statistics’ 2003 Survey of Disability, Ageing and Carers [SDAC]).

**Age-standardised rate**
A method of adjusting crude rates to eliminate the effect of differences in population age structures when comparing for different periods of time, different geographic areas and/or different population sub-groups.

**disabling condition**
A disabling condition is a “disease, disorder or event that leads to an impairment or restriction that has lasted or is likely to last for at least 6 months”. [SDAC]

**incidence**
The number of new cases [of ABI] within a given period.

**main disabling condition**
A “main disabling condition” is, in circumstances where multiple conditions are, the one reported as causing the most problems.[SDAC]

**participation restrictions**
Participation restrictions are “problems an individual may experience in involvement in life situations” such as attending school or participating in recreation. [SDAC]

**young people**
This submission uses the Australian Institute of Health and Welfare’s (AIHW) “young people” as those aged 12–24 years. (Defining young people as those aged between 15 and 24 years is also a widely accepted statistical convention and is used by many studies on youth.)
ENDNOTES:

1 Australian Bureau of Statistics 2004, Table 17, Disability, Ageing and Carers: Disability and Long Term Health Conditions, Australia 2003, Canberra

2 “Interpersonal relationships and work may also be affected. This large group of people with TBI can face many years of impairment, possibly affecting health, education, occupation, and social and emotional functioning.” (Medical Journal of Australia Practice Essentials – Rehabilitation 4: Rehabilitation after traumatic brain injury”, Fary Khan, Ian J Baguley and Ian D Cameron Medical Journal of Australia, 2003, 178 (6): 290-295)


5 “However, this unemployment rate for people with an acquired brain injury includes those people who are permanently unable to work because of their disability. If this latter group is excluded, then the unemployment rate for people with acquired brain injury drops to 15 per cent. This is the difference between those who are not in the labour force and those who indicated in the survey that they were permanently unable to work. The unemployment rate for people with acquired brain injury capable of being in the workforce is therefore almost double that of the total Australian unemployment rate.” Brain Injury Australia, “Acquired Brain Injury Employment Study”, prepared for the Department of Family and Community Services by Jeffrey McCubbery, Dr Chris Fyffe, Kris Honey, Susanne White and Jenny Crosbie, 2002 (unpublished).


7 “This did not mean that people did not need intensive support or support from time to time. It was more a question of what was available was not accessible, relevant or have the capacity to keep in touch with people over the years.” Brain Injury Australia, 2002.

8 21 May 2008, Press Release, Department of Prime Minister and Cabinet – “Prime Minister and the Deputy Prime Minister will today attend the first meeting of the new Australian Social Inclusion Board...”

9 “Children from low socioeconomic backgrounds and Indigenous Australian children...have a higher risk of injury and death from injury than other Australian children. Children from low socioeconomic groups are more likely to suffer injury from certain causes, such as house fire or assault, which are more often fatal than other causes of injury. The likelihood of a child being injured or killed has also been associated with single parenthood, low maternal education, young maternal age at birth, poor housing, large family size, and parental drug or alcohol abuse.” Australian Institute of Health and Welfare, Key national indicators of children’s health, development and wellbeing; indicator framework for A picture of Australia’s children 2009, Canberra, 2008.

10 “Long-Term Outcomes After Traumatic Brain Injury: Following Up A Consecutive Series At 20-26 Years Post-Trauma - Final Report To Motor Accidents Authority Of New South Wales”, R Tate et al. Rehabilitation Studies Unit, Faculty of Medicine University of Sydney, 2004

12 Ibid.

13 Ibid.

14 Brain Injury Australia to Senator the Hon. Joe Ludwig, Minister for Human Services, 2 April 2008.

15 “People with an Acquired Brain Injury in this sample of services comprised 6.5 per cent of the total number of people with disabilities in these services. There were notable exceptions to the national average. In the Northern Territory, respondents reported that of the total number of job-seekers, 18 per cent were people with acquired brain injury from Indigenous and isolated populations. Brain injuries were reportedly due to alcohol, drug and other substance use. In Western Australia and New South Wales, there were significantly higher numbers of job-seekers with acquired brain injury, probably because of employment services specialising in acquired brain injury”, Brain Injury Australia/ McCubbery, 2002.

16 “Wehman (1991) cited a study that showed once people with traumatic brain injury had been in jobs six to nine months, their long term vocational status improved. The high risk period was the first few months at work—hence the need for long term support for people with acquired brain injury once they become employed.” Ibid.


18 “Investigation of factors related to employment outcome following traumatic brain injury: a critical review and conceptual model”, Tamara Ownsworth And Kryss Mckenn, Division of Occupational Therapy, School of Health and Rehabilitation Sciences, The University of Queensland, Disability And Rehabilitation, 2004; Vol. 26, No. 13, 765–784.


