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BRAIN INJURY AUSTRALIA:

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

April 2011

B R A I N I N J U R Y A U S T R A L I A

Brain Injury Australia is the national peak acquired brain injury (ABI) advocacy organization representing, through its State and Territory member organizations and network relationships, the needs of people with an ABI, their families and carers. The major components of ABI 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 organizations.

BACKGROUND:

Brain Injury Australia received funding from the Australian Government's Department of Families, Housing, Community Services and Aboriginal and Torres Strait Islander Affairs' (FaHCSIA) "Community Engagement Strategy". The funding was for the purposes of "engaging people with disability, their families and carers in the Productivity Commission's Inquiry into long-term care" ("the Inquiry"). Brain Injury Australia used part of that funding in employment of a short-term Project Officer to prepare, in collaboration with its State and Territory Member Organisations, a "first-round" submission to the Inquiry.

The Inquiry's "Issues Paper" includes the following; **"an overall criterion for eligibility [to any proposed scheme of disability service provision] might be those people for whom the expected benefits of additional resourcing and better service coordination would be greatest. Factors that could be relevant in deciding this are where: local support and resources are low (some country areas) or where general disadvantage is combined with disability (some Aboriginal and Torres Strait Islander communities)."** At its November 2010 meeting, the Board of Brain Injury Australia determined to use the balance of the "Community Engagement Strategy" funding to conduct consultations with people with an ABI, their families and carers living in regional, rural and remote communities.

RATIONALE:

While Australia is often thought of as one of the most highly urbanised countries in the world, nearly one-third of its population lives outside major cities. And that population is growing at rates that almost match metropolitan Australia; by 11% between 2001 and 2009, compared to 14% for its cities. **People living in regional, rural and remote areas, men especially, are more likely to have a disability, including ABI, than those living in major cities.**¹ While one survey found no significant differences in outcomes from traumatic brain injury (TBI) for 200 patients living in urban and rural New South Wales, it is Brain Injury Australia's consistent experience that **access to services and supports relevant, let alone specific, to the needs of people with an ABI, their family members and carers remains patchy and unreliable.**²

Generally, Australians who live outside major cities are more likely: to rate their health as poor; to have had a long-term health condition which occurred as a result of an injury (such as an ABI); and to experience alcohol-related harm through violence, acute and chronic health problems, and drink driving.³ Brain Injury Australia welcomes the Council of Australian Governments' acknowledgement of the specific needs of people with a disability living in regional, rural and remote Australia in its "2010–2020: National Disability Strategy" – its "ten year national plan for improving life for Australians with disability, their families and carers";

"Additional stresses are often faced by people living in rural and remote areas. Remote areas are characterised by low population density and a lack of access to larger service centres and transport routes. This can limit equity and access to services, and where services are available, providers sometimes face difficulties in recruiting and retaining an appropriately qualified workforce. The characteristics of rural and remote areas can provide challenges for people with disability that are distinctly different from those for people who live in metropolitan areas. The Strategy takes an approach that is comprehensive while recognising the different needs, perspectives and interests of people with disability. Recognition of the diversity of experiences of people with disability underpins the six outcome areas of the Strategy."⁴

Aboriginal and Torres Strait Islander people are three times as likely to experience ABI as the rest of the Australian population. Brain Injury Australia also notes this statement from the Strategy;

"Aboriginal and Torres Strait Islander people with disability are among the most disadvantaged members of the Australian community. They often face multiple barriers to meaningful participation in their own communities as well as the wider community, facing double disadvantage because of discrimination on the basis of their Aboriginality as well as their disability."

Just as people with a disability living in regional, rural and remote Australia are less likely to have ready access to services and supports than those in major cities, they are also less likely to be consulted with in regards to their unmet needs or asked for their vision of a "*real* system for people with a disability".⁵ It is with this in mind that Brain Injury Australia and its Member Organisations determined to conduct these consultations, described below.

METHODOLOGY:

Brain Injury Australia enlisted expertise from Life Without Barriers (LWB) to conduct and report on the consultations (LWB's report forms the basis of this submission). Brain Injury Australia also sought local support for organisation of the consultations from its State and Territory Member Organisations. Consultations were completed in New South Wales, Tasmania and the Northern Territory during March and April 2011 with specific locations within States and Territories determined by state Member Organisations. Invitations were produced by LWB and Brain Injury Australia, published on Brain Injury Australia and Member Organisations' websites and then distributed through consumer and service provider networks. Local advertising was also undertaken in Tasmania. Consultations were facilitated by a LWB facilitator and notes were taken of the proceedings either by a LWB or by Brain Injury Australia's Member Organisation. A PowerPoint presentation was used to introduce the topic to the audience and then the discussion was facilitated by using the following prompt questions:

- *What are the barriers to people with a ABI having a good life?*
- *What would it look like if these barriers disappeared?*
- *What would give you confidence that you, or your family member would be cared for throughout their life?*
- *Should there be more of some types of services?*
- *Should there be new types of services?*
- *How could a new disability support system be funded?*
- *Do you think a no-fault insurance model could work?*
- *What might the problems be?*
- *What is the best and fairest way to work out who most needs financial support and services?*
- *How could we ensure that people with a disability and their families have more control over the services they receive?*

LOCATIONS AND PARTICIPATION:

The following table shows the locations and participation in the consultations.

Location	People with a ABI	Family members	Service providers	Other	TOTAL:
Hobart	8	3	7		18
Burnie (TAS)				1	1
Launceston	7	6	9		22
Bathurst (NSW)	2	1	2		5
Lismore (NSW)	1	4	1		6
AliceSprings (NT)	13		7	1	21
Mutitjulu*	7	3	4		14
TOTAL:	38	17	30	2	87

* Mutitjulu is an Aboriginal and Torres Strait Islander community 350 km south west of Alice Springs. Note: some consultations were conducted individually in Alice Springs and Mutitjulu.

KEY THEMES:

1. ABI is a “hidden disability”

Participants reported poor understanding of ABI within the medical, allied health, and disability professions. This has led to unsuitable or inappropriate treatment from doctors, therapists and support workers engaged to support people with an ABI. It can also lead to misunderstanding in the community where people with an ABI are excluded from mainstream services because they are considered to be under the influence of alcohol or other substances and/or mentally ill. Many participants commented that rehabilitation workers often do not recognise or understand the need for cognitive-behavioural as well as physical rehabilitation for people with a ABI.

One participant in Tasmania noted that her husband had seen more than fifty doctors before he was correctly diagnosed with an ABI.

A woman in Lismore commented that the disability support workers who have supported her son over the years have been focussed on supporting people with an intellectual disability, and do not understand that people with an ABI have different needs.

There is also a very poor level of knowledge of ABI among the broader population. This leads to a general lack of understanding of the challenges faced by people with an ABI and their families and carers. In addition, people with an ABI present in a range of different ways, and have very varied impairments. People with an ABI can look “normal” therefore people do not understand that ABI is an ongoing disability that can cause many cognitive and behavioural challenges.

A Hobart man with an ABI commented “because I look ‘normal’, people don’t understand that I have trouble crossing the road or managing money”.

A disability support worker in Alice Springs said that a client with an ABI she supports is regularly denied access to public transport because the bus drivers assume she is drunk.

Participants at the consultations reported that people also perceive ABI as a self-inflicted disability, that people with the disability are subjected to blame and are thought undeserving of services and supports. This translates to additional challenges for people with an ABI and their families. This view was represented particularly strongly during the consultations in the Northern Territory: participants said that there was often limited community empathy or support for people with ABI, particularly where it was known or believed to be associated with alcohol or other substance abuse.

The consultations revealed widespread concern that people with a ABI would not be catered for under a new scheme, or would “miss out” on services. A service provider in Tasmania expressed concern that if the scheme was based on diagnosis, then people with an ABI would not be able to access support. There was strong consensus that the scheme should be based on reported need - rather than professionals’ judgment of what might constitute “severe” or “profound” disability – and regardless of the ABI’s external cause. Participants also urged that, due to the episodic needs often associated with ABI, that a person’s needs must be regularly re-assessed over time.

2. The impact of ABI on families and relationships

Participants with an ABI and their family members regularly commented on the impact of the disability on a range of relationships - for example, when a family member becomes a carer.

A man in Hobart commented that his wife had started to become his carer, when she needed to assist him to cross the road and perform other daily living tasks, "but she wants to be my wife, and I want her to be my wife, not my carer".

If an independent carer was available, relationships could go back to more normal partner or family relationships. But participants regularly reported that the services, where available in their area, are not adequately targeted towards providing support to family members who double as carers, such as respite services and home help services. **An almost universal opinion of participants at the consultations across all locations was; people want services that support them *within* their families. They also want services that support their families *to care for them*.**

A woman in Launceston commented that there were no services or supports available to assist her to fulfill her role as a mother within her family after her ABI. She was unable to access support to do the range of day-to-day tasks that would normalise life for her children. In addition, there was nothing available for her children in the form of direct support, or to help them to understand their mother's disability. Another man in Launceston had sought assistance in explaining his wife's ABI to their young children, and was not able to access any help or support in this regard.

In this regard, participants from remote communities stated they were especially vulnerable. There are very limited services available in those communities, so families are forced either to also act as carers or relocate to major population centres where services are more readily available.

One man in Alice Springs was only able to visit his community when two workers were available to travel the vast distance to drop him off and pick him up, and family and community members were available to meet his needs during the visit.

Many participants complained that a lack of certainty and predictability in funding made it impossible to plan for the care of a loved one with an ABI. This was particularly the case for ageing carers in regional, rural and remote areas who were concerned about the supply of local, and dependable, care supports. A number of participants in the Lismore consultation, who have been caring for their adult children with an ABI for many years, shared great anxiety about their children's future, as they had no sense of certainty regarding the provision of funding and support.

3. Poor access to services

Participants pointed to the very limited availability of specialist services for people with an ABI in their localities. Participants spoke of their exhaustion with the “struggle”, the “fight”, to access generic services that appear to be targeted primarily towards people with a physical, sensory or intellectual disability or those with a mental illness. They then felt that they could never express any dissatisfaction with whatever generic services were available locally, at the risk of being denied access to the little they had. There was also very limited information available about what services exist and how to access them, with people feeling confused, “in the dark” about whom to ring, to talk to and how to find out what was available in their area.

One participant in Bathurst recounted his story of receiving treatment in a Sydney hospital, then being moved to Bathurst Hospital - which has a specialist ABI rehabilitation unit - and then being sent home to a town in the Central West of NSW. He had no idea what services were available to him in his area, and was not provided with any information as he was leaving hospital.

People in regional areas are required to travel great distances to access specialist services. This can be extremely difficult for people with an ABI. This theme came through very strongly from participants in the Alice Springs, Mutitjulu, Lismore and Launceston consultations. People in Launceston (population; 103,000) were very vocal about the need to travel to Hobart to be able to access specialist services, even to simply consult a neurologist. Participants at the Lismore (population; 43,000) consultation expressed frustration at the need to travel to Sydney to access services, while not being able to access services in Brisbane – because they’re not Queensland residents - despite Brisbane being much closer. It was noted by a number of people in Mutitjulu (population; 300-400) how people “go without” rather than travel away from their country and family. (Across all the consultations, people with an ABI and their family members noted that performance on important neuropsychological and other assessments for the disability was severely impacted by fatigue due to travel requirements.)

Participants related that ABI-specific rehabilitation services, where available, are time-limited and often from only one location rather than being available at a time and place – the client’s home, for example – to allow for their maximum effect. They were only able to access rehabilitation services after leaving acute, hospital-based, care for very limited times. They were unanimous in their preference for people to be able to access “slow stream”/ long-term rehabilitation support in the home. This was a very significant issue mentioned in all consultations. Participants complained of often arbitrary-seeming limitations and rules around services; for example, what can be provided under a particular service type or funding category or what type of house-cleaning can be provided. Participants at the consultations were clear on this; providers systematically fail to place client need at the centre of service delivery.

Co-ordinated, and long-term, case management was the service type most mentioned as being desirable but unavailable. Participants in some areas were able to access services in the short-term, but these were manifestly inadequate at sustaining change, particularly with ongoing cognitive and behavioral impairments for people with an ABI. This left participants feeling that they were inadequate at identifying and securing services, in negotiating “the system”.

Participants complained about the lack of choice in services; for example, that the only accommodation option was a nursing home, or group home with inappropriate housemates.

One carer from Lismore commented that her son with an ABI, who is in his early thirties, “lives with three women in their fifties with intellectual disabilities. The women all socialize with each other. He is not interested in going to the sorts of things these ladies are interested in. He chats to the staff more, but it is not a good match for him.”

A man in Hobart commented that his son lived in a nursing home as that was the only accommodation available to him, and he is a young man surrounded by people who are dying. This is having a significant deleterious effect on his mental health, and he is becoming very concerned with the thought of his parents dying.

People wanted access to a greater range of generic and specialist services closer to where they live. They wanted fairer and easier access to services.

4. The need for more of particular types of services

Participants at the consultations identified long-term case management as their most significant unmet service need. Specifically, people felt that the biggest service gap was someone to be available to them throughout the progression from acute care, then sub-acute rehabilitation and then to home - realistically someone who is knowledgeable about ABI and what local services are available and able to provide ongoing support and information. Rehabilitation services made available over the long term were also identified as a key service type ordinarily unavailable to people with an ABI living in regional, rural and remote locations. Specifically, participants emphasised their need to access rehabilitation services that are not only accessible locally, but also flexible in their timing and intensity. Rehabilitation should be made more readily available in the home environment, both at a time that was suitable to the person with a ABI and their family and at a time when it is likely to have the greatest impact on recovery. **Participants were also concerned that people with an ABI were often unable to access rehabilitation services with expertise and capacity specific to the disability, especially in cognitive and behavioural areas.**

Participants wanted accommodation support that is flexible and makes choice possible. People with an ABI want access to accommodation options that match their needs. Accommodation suitable for younger adults with an ABI - as opposed to residential aged care facilities – was mentioned regularly by participants, as was the need for short-term crisis accommodation. Homelessness was mentioned as a major risk for people with an ABI, who often find securing stable and long-term employment challenging (to meet rental payments, for example) unless they have a high level of family and community support.

Flexible in-home or community-based support services were also seen by many participants as key – for example, for household cleaning, transport, social support, shopping etc. These services need to be provided in addition to attendant care, for example. Greater flexibility in attendant care was also seen as a priority. These services should include options for in-home and centre-based respite.

Transport services were seen to have the potential to improve the day-to-day lives of people with an ABI, as it can enable access to community. This is a critically important issue for people living in remote and very remote areas in order to access services and maintain relationships with family and community.

5. The need for a scheme in which eligibility is based on need, rather than diagnosis

Participants in all locations voiced great concern that people with an ABI will not be able to access services and supports under scheme proposed in the Inquiry's draft report. Where eligibility is restricted to disabilities assessed as "severe" or "profound", when combined with a focus they perceived on physical, sensory and intellectual disability, many participants feared the proposed scheme would simply fail to capture some of the cognitive and behavioural subtleties of ABI. This was related in the consultations to ABI simply not being recognised as a disability in the direct experience of many participants, and to locally available services being targeted at other disability types.

Participants strongly wished for a scheme under which people's needs – regardless of disability type or cause - are the determining criteria for access. And that people with an ABI are reassessed throughout their lives as their needs change, so that the provision of funding and support is timely, fair and equitable. Participants also felt a needs-based scheme would help address the common perception of people with an ABI as being undeserving of support.

6. The need for increased flexibility, choice and control

The consultations highlighted the diversity of life circumstances faced by people with an ABI and their families living outside metropolitan Australia, and the wide range of needs and priorities. However, participants were unanimous in wanting services to be locally available to respond to their unique needs. **Participants in remote areas were especially adamant that accessing necessary services should not require people with an ABI be separated from their families and communities. This was crucially important for Aboriginal and Torres Strait Islander participants.**

Under any scheme proposed by the Inquiry, some participants with an ABI expressed the wish to manage their own funding. Others preferred a nominated guardian or case manager manage funds on their behalf. Some participants with an ABI shared their difficulties with managing money. They were concerned about being disadvantaged in, or simply ineligible for, a scheme that required self-management of funding. The ability to appoint – and for them to choose - someone to manage funding was seen as a key aspect of any proposed scheme. All participants recognised that identifying people who lacked the capacity to self-manage funding, in a way that was fair and equitable, would be one of the challenges of the scheme. The issue of funding management was raised repeatedly in Alice Springs and Mutitjulu. Concerns were expressed there about how people would manage their money, how they would purchase services and whether any new scheme would afford opportunities to pool or share funding. **A strong view was expressed that the Inquiry needed to make recommendations specific to the disability care and support needs of people with an ABI living in remote and very remote communities.** (Throughout the consultations, participants pointed out that self-managed funding would be meaningless in locations where there was no choice in service provision.)

The importance of disability funding being portable was mentioned throughout the consultations, both in allowing people to readily move between jurisdictions but also access services in adjacent States or Territories where they live closer to borders than regional or metropolitan centres. Lack of such portability was a particular frustration of participants in Lismore, as per above, as well as those living in the tri-state area of Central Australia. Participants in all locations related experiences of moving interstate and having to “start again” in accessing disability funding and support, and in navigating another State or Territory’s service system.

7. The need for changes to the service sector

Participants in all locations identified a range of reforms to the disability service sector that would need to accompany any new “care and support” scheme. These reforms were seen as essential, whatever other features the new scheme entails. For instance, **it was participants’ regular experience that staff working in the disability sector are often not sufficiently skilled or trained. Participants in a range of locations suggested that people were “taken off the street” to work in disability support, that they had minimal training and were poorly paid. And while they displayed a generally developed understanding of sensory, physical and intellectual disability from working with such clients, most had little exposure and demonstrated limited knowledge of ABI.** Participants also reported that the disability-relevant coursework offered by most universities and colleges of TAFE contained very limited content about ABI, so that health and allied health professionals demonstrated an often inadequate understanding of the support needs of people with a ABI.

Participants expressed concern about the quality of disability services in some locations. They also noted there was little or no monitoring of service quality, with manifestly poor services appearing to not only have their funding renewed, but increased. There was a very strong suggestion that assessments and ongoing monitoring of service quality should place the experience of clients and their families at their centre.

¹ “Males in Inner Regional and Other areas (Outer Regional and Remote) have significantly (1.2 to 1.4 times) higher rates of psychiatric disability, sensory/speech disability, acquired ABI and physical/diverse disability”, Australian Institute of Health and Welfare 2008. *Rural, Regional and Remote Health: Indicators of Health Status and Determinants of Health. Rural Health Series no. 9*

² “Severe traumatic ABI in New South Wales: comparable outcomes for rural and urban residents”, Peter G Harradine, Julie B Winstanley, Robyn Tate, Ian D Cameron, Ian J Baguley and Ross D Harris, *Medical Journal of Australia*, 2004; 181: 130–134

³ “Australian Social Trends, 2011”, Australian Bureau of Statistics, March 2011

⁴ “2010–2020: National Disability Strategy”, Council of Australian Governments, February 2011

⁵ “Draft Report; Disability Care and Support, Overview and Recommendations”, Productivity Commission, February 2011, p.5