TO: Inquiry into Disability Care and Support
Productivity Commission

FROM: BRAIN INJURY NETWORK OF SA INC (BINSA)
SUBJECT: BINSA SUBMISSION TO THE PRODUCTIVITY COMMISSION'S INQUIRY INTO DISABILITY CARE AND SUPPORT
DATE: 16 AUGUST 2010

1. Is need the appropriate basis for eligibility?

BINSA supports need as the more appropriate basis for assessing eligibility, from a diverse evidence basis that is appropriate to someone with an acquired brain injury (ABI), including a medical diagnosis.

- ABI needs can cross many domains: physical, sensory, emotional& behavioural, thinking and mental processes.
- However, need cannot be divorced from a diagnosis and so overlooking a diagnostic group entirely would not be advisable.
- 'Need' is a nebulous term and therefore must be closely defined by assessment criteria (suggestions for these criteria outlined below).
- A functional assessment alongside diagnosis may be a dual pathway to establish need.

There are already a number of NATIONAL/STATE assessment tools in place – eg Work cover type assessment, state Disability case management assessment, job assessment and so on, so there are options that use non diagnostic assessment as well as 'medical' diagnostic assessment – what is important for ABI is we need a measure that is across all the cognitive factors as well as physical and psychological assessments so there is a clearly definable 'evidence' based approach in establishing need.

There are also other tracking tools that allow various assessment – e g medication histories (now on e track and linked to Medicare), use of publically provided support services (housing, Dom care, home care, etc) and so on – these are measurable and definable 'needs' that can be used in assessing the broader need outside of the medical diagnostic assessment – as we know those with an ABI are sometimes reluctant or not aware of the disability they have

2. What groups have the highest needs or have been most disadvantaged by the current arrangements?

BINSA believes that the following groups of individuals who have suffered an ABI have been most disadvantaged by current arrangements:

- Those in the criminal justice system;
- Indigenous Australians and CALD groups;
- Remote, regional and rural populations;
- Dual diagnosis: ABI and mental health;
- Homeless population;
- Alcohol and other drug-related ABI;

- Mild to moderate ABI through a traumatic injury (TBI), eg concussion and
- Children with ABI.

A good idea would be to define what we mean by mild or moderate? In an ABI situation there may be a need to consider the notion of having specific categories of need – and that each category have an entitlement to a level of service – so that none actually miss out – this is esp. relevant to those with an ABI.

3. Is severe or profound disability an appropriate criterion for the need for support?

BINSA supports severe or profound disability as an appropriate criterion for the need for support, but also suggest that it is only one aspect of the complex equation of what it means to be disabled through having an ABI.

A mild/ moderate traumatic (TBI) ABI refers to the level of injury to the brain. This must be separated from the disabilities that may result from such a TBI. Whilst a mild/ moderate TBI may only cause limited physical impairments, the cognitive disabilities may be long-term and debilitating. Therefore, some mild to moderate TBIs do result in disability that is severe and profound. BINSA believes that any assessment of need as a basis of eligibility for the scheme must take into account cognitive-behavioural as well as physical impairments/disabilities. True needs based assessment will therefore recognise that some of those people with a mild TBI would be eligible due to the severe and profound cognitive disabilities that have resulted.

Regardless of the level, an ABI is severe and profound but a distinction is in the level of need - which may be quite small depending on the ABI – so what we are wanting is that there is recognition of the fact that different disabilities will have different 'descriptors' for severe and profound rather than an all in one - and this is where an appropriate assessment tool will become essential as a measure

4. What are the appropriate features of assessment tools?

BINSA supports an assessment process with a flexible assessment tool that has the elements of that disability – so for ABI that needs to include, cognitive, physical, and psychological and so on. Given that all states and territories have specific ABI clinical and rehabilitation units, where this assessment is standard fare then this is where we suggest that assessment tools be developed as they are the experts.

The assessment should be made by a panel or using a methodology that has input from at least one person with ABI expertise and one consumer representative. The assessment criteria must be measurable and BIA understands that there are a number of nationally available, scientifically verifiable tools that are currently used which could be appropriate for the assessment process. These include tools which classify by diagnosis, severity and functional ability.

5. How should carers' needs be factored into eligibility?

BINSA considers that carers' needs are very important, especially given the significant financial and social cost to the community of a higher than usual incidence of family breakdown following brain injury. Carers need greater information, support and direction which could be achieved through assigning an advocate or support worker to the family.

This is an opportunity to make carers allowances and so tied to the assessment outcome of the individual who is approved for an NDIS –so there is not the need for constant reviewing of eligibility as there is at present.

6. How should the scheme address disability associated with natural ageing, and why?

BINSA would support the option outlined in the Issues Paper that the scheme only covers people aged less than 65 years (increasing to 67 by 2017 in line with the Age Pension qualifying age). This would be a simple and objective criterion and would include ageing-related conditions up to age 65 years and exclude non-ageing related sources of disability after age 65 years. Reasons for this include:

- Surety of budgeting and funding;
- Eliminating the need for jurisdictional migration;
- National consistency ensuring access to specialist medical and allied services that are located in key centres; and
- Removal of discriminatory practices that arise from 'siloing' between federal and state programs.

BINSA further supports the underlying principle that, irrespective of age, if a person has an entitlement to treatment then treatment should be provided. The cost allocation for that treatment should be dependent upon the program or programs that support that individual. Further, there should be supported transitions to aged care services.

7. What are the most important services, their costs, their likely demand and who would be the predominant users?

BINSA supports services that are 'life-long' relative to the timing of the individual acquiring the disability. In particular, BINSA considers it essential that a scheme be responsive to the periodic needs for services and support experienced by many people with an ABI. A short-term, time-limited approach is not the answer and there should not have to be a crisis in order for a person with ABI to reengage with services and supports. BINSA supports the following are the most important services for people with an ABI:

- Early intervention: sub-acute rehabilitation services and brain injury specific rehabilitation services including: retraining in activities of daily living; pain management; assistive technology; environmental manipulation; cognitive and behavioural therapies; speech therapy, pharmacological management; psycho-social community-based rehabilitation; counselling and relationship support and psychiatric follow-up;

- Training for support workers and family members: to address the systemic lack of knowledge of how to work effectively with people with an ABI;
- Individualised case management: coordination of total requirements throughout eligibility period, including advocacy services, employment support and tertiary education support;
- Local area coordination: essential to have an appropriate continuity plan/transition from hospital to home, inter-agency (health, disability, mental health sectors) protocols to be developed following ABI and complex needs research to identify and address systemic barriers;
- Accommodation – minimum 'check' list so the more common aspects of ABI needs are covered and or addressed and subject to regular review eg change in financial circumstances, changing ability to organise
- Regular publicity campaign to raise awareness and deliver appropriate information.

8. How would services be structured to increase the likelihood of participation in the work and community?

BINSA advocates for a performance measure that incorporates community participation and engagement in workforce (where appropriate) as key outcome and able to be demonstrated by the service system. The disincentives to improve circumstances need to be removed e.g. losing entitlements if commences work.

BINSA supports a mix of public and private as well as NFP so that there was choice and also more available and accessible services – could be a contestable service marketplace. This would require improved service contracting – that is at last 3 year contracts for services – preferring up to 5 years so there was certainty – this was to be matched with high quality checks to ensure compliance and national service standards being met

9. How should services be monitored and regulated with respect to quality, outcomes and cost effectiveness?

BINSA considers that there are a number of reputable, independently audited, quality systems. These systems are readily adaptable and when combined with individual client feedback evaluation mechanisms can provide a comprehensive reporting and accountability process. In addition, quality management would provide for the monitoring and regulation of services.

Cost effectiveness should be considered in relation to the effectiveness of programs to deliver to clearly define outcomes; defined in objective and consumer centred (self-determination) terms.

10. Costs, risks and benefits - How should unmet needs be measured?

There are currently very poor and almost non existent reporting/data sets relating to demand and service requirements. Therefore, a national disability scheme needs to include a commitment to effective and comprehensive data collection.

If NDIS is introduced then it will be essential to have national consistent data reporting and client record tracking where appropriate profiling could be achieved

11. How much do various services cost (for example, attendant care, accommodation, day centres), and what pressures are on these costs?

The economic burden of ABI in the acute-care setting is substantial. Treatment costs and outcomes vary considerably by ABI severity and mechanism of injury. A TBI ABI commonly affects younger people and causes life-long impairments in physical, cognitive, behavioural and social function.

Additional areas where little support exists currently includes: the cost of those with an ABI in prison, mental health services etc and other costs incurred by the community and government where services are not provided for people with an ABI.

12. Comprehensive vs. narrow coverage

BINSA supports comprehensive coverage. Implementation should be at a point in time rather than a transitional approach. Good examples of a point in time approach for national systems include Medicare and GST. A transitional approach example is the current Fair Work Act that has seen a dramatic increase in confusion across the industrial relations area.

13. Individualised funding

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

BINSA supports individualised funding for its constituents. This will facilitate a service system that is far more responsive than existing group or block funding models. It should follow the individual across the health, mental health, occupational rehabilitation and disability service sectors.

BINSA is keen to reinforce this point: the issue is that we want flexibility in assessment because ABI may appear 'mild' but be severe and profound as it's injury to the brain. We have also said that the care/support/ needs may be intermittent – so therefore we need a 'life cycle ' approach rather than constant reassessment – so the individual is not forever having to re-qualify etc. this has impacts on carers too

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