Headwest Brain Injury Association WA Inc.

Submission to the Productivity Commission

Long Term disability Care and Support Inquiry

1.0 Introduction

1. Headwest Brain Injury Association of WA (hereafter called 'Headwest') makes this submission to the Productivity Commission Inquiry into long term disability care and support.

   This submission is based on the findings of interviews with carers and people with acquired brain injury, and of focus groups held for the Inquiry with disability advocates, disability, mental health and health professionals, research and policy personnel, Aboriginal stakeholders, and professionals in disability social inclusion[1].

   Headwest is the peak advocacy body for people with acquired brain injury and carers in Western Australia. The organization advocates for individuals and families, and conducts systemic advocacy. It is funded by the Disability Services Commission.

2.0 Summary

4. This submission is a response to the Productivity Commission's request, in its Issues Paper, for comment on the design implications for a National Disability Insurance Scheme, or similar scheme for the long term support and care of people with disabilities.

5. The aim of the Inquiry, to address systemic and enduring inadequacies, the 'broken-ness', of the disability sector, is commended. For many people with acquired brain injuries and their families in Western Australia, the system is not just broken; it barely exists at all. While some people with acquired brain injuries have access to disability services, many remain serviced by Health, as outpatients or in long stay wards, or are in Mental Health institutions, or are in prison.

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[1] Four focus groups were held by Headwest, with 31 participants in total:

1. Disability Advocates Focus group (6 participants), held with PwDWA.
2. Disability, mental health and health professionals, research and disability policy personnel Focus Group (9 participants); Social Inclusion Focus Group (6 participants). Research facilitation and preliminary analysis of findings conducted by Dr Caroline Bulsara, School of Primary, Aboriginal and Rural Health Care, University of WA.
3. Aboriginal stakeholders (10 participants), held in with the Aboriginal Health Council of WA. Research facilitation and preliminary analysis of findings conducted by Aboriginal Elder Dr Michael Wright, Kulunga Research Network, Telethon Institute for Child Health Research.

Two in depth semi structured interviews were also conducted. Findings are credible and are consistent with Headwest's broader practice findings in advocacy for and with people with acquired brain injury and carers.

6. Headwest commends the consideration by the Productivity Commission that the scheme design should address the systemic failures of the current disability sector, and build on elements of the current system that demonstrate an effective response to the needs of people with disabilities and their families.

7. Headwest considers that the following principles should inform the design of the National Disability Insurance Scheme, or similar scheme:

- **Substantive Equity** - Eligibility for the Scheme should be broad, and based on disability support and rehabilitation needs and considered with contextual variables, like social, economic or cultural disadvantage.

- **Human Rights & Social Justice** - The Scheme should encompass the social model of disability and promote self determination as held by the Convention on the Rights of Persons with Disabilities; and the Scheme should redress Aboriginal disability disadvantage, closing the gap. There should be a focus in the empowerment of individuals in self-advocacy and self determination, and the provision of independent advocacy services to protect and promote the rights and interests of people with acquired brain injury and their families/carers.

- **Efficiency** – The Scheme should facilitate a person centred approach and inter-sectoral collaboration, to optimise health, rehabilitation and recovery outcomes and minimise the disabling effects of brain injury, with the person at the centre rather than services.

- **Sustainability** – The Scheme should focus on reducing the incidence of injury, and it should facilitate rehabilitation, recovery and social inclusion (social, cultural and economic) for long term social and economic sustainability. The Scheme should direct attention from short term costs to long term outcomes. It should provide the disability care and support services that people need, and in doing so, it should focus on reducing the demand for services across government, particularly in health, mental health, justice, homelessness services, and aged care.

8. In response to the Productivity Commission's statement that the focus on the Inquiry is 'how to build a good system', Headwest recommends that the new system is established to:

   A. Reduce the prevalence of acquired brain injury;
   B. Provide a comprehensive early intervention approach;
   C. Promote best practice pathways to rehabilitation and recovery; and
   D. Ensure disability care and support services address needs, and that they promote social and economic participation.

3.0 Design of the scheme

9. Headwest recommends that the following specific design issues be incorporated into the proposed scheme:

Eligibility

10. Eligibility should be broad, and available: to anyone who needs disability support and care to help with core activity tasks for daily living, and to assist their social and economic participation; and, so that they can exercise their human rights; in accordance with the *Convention on the Rights of Persons with Disabilities (CROD),* the *Disability Discrimination Act (Cwth)*, 1992, and the *International Classification of Diseases (ICD 10).*

11. Eligibility should be determined on the basis of an assessment by the individual, in conjunction with an objective functional needs assessment and medical records:

> Anybody that needs disability care and support should be eligible for the new National Disability Insurance Scheme. I mean, how could they set up and exclude. On what grounds would they exclude somebody? It's like, with me, because I have tried to do without various services, I have had to justify that I am brain injured and I wasn't somebody who took advantage.
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> I've moved around quite a lot, so I haven't got records and shown everything, why do I need to justify that I am disabled, it's like anybody can see I am disabled. So to me, and yet I can understand on one hand they can have different criteria. But to me I think that it should be imperative that if someone requires a service, and you can see that they need it, if somebody was saying … and I've met these people, people who abuse the system … like I met this woman who identified all these things, and she did not need half of them…. this makes us suffer because then there are people who miss out because of this. But how am I to decide who needs and who doesn't. I think if it comes from the person, then the person knows what they need.
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> Most people are honest. Why would I or anyone identify as being brain injured if I didn't need to be, why would I identify as being disabled if I wasn't? To me it's obvious. (SSI, HH2807201)

12. People over the age of 65 should, at present, be the responsibility of the aged care system; provided that aged care services provide the range of services required by people with acquired brain injury, including care coordination, particularly for people with complex needs.

13. A further community debate is needed about the age limit, as the life expectancy is such in Aboriginal communities that people over the age of 50 are considered to be Elders; while on the other hand, life expectancy in the mainstream population is extending, with an increasing expectation that people will remain in the workforce beyond the age of 65.

Assessment

14. Assessment should be conducted through a simple application process. The assessment process should be available in alternative disability access formats. They should also be made available in culturally secure formats for Indigenous communities. Translated versions and interpreter services should be available to applicants who are from non-English speaking backgrounds. Alternative and culturally secure formats, and translation and interpreter services should be provided at no cost to the applicant.

15. There should be a process for three yearly reviews, or reviews should be conducted at points of life transition:

> Ideally, each person's situation would be reviewed every three years, with small reviews in between, so that services and supports are tailored to the changing needs; or the person and his or her family may have a plan based around a review at key life transitions and flexible to address crisis, say a crisis plan to redress a risk of homelessness. The family should be involved in the design and review of the plan. The plan should be based on what the person chooses, and the plan should allow the person to do whatever the person says they want or need to do (SSI – GP20072010).

Coverage of the scheme

16. The scheme should cover health promotion and injury prevention, disability care and support, and research.

17. The scheme should cover:

A. Reducing the prevalence of acquired brain injury;

B. Providing a comprehensive early intervention approach;

C. Promoting best practice pathways to rehabilitation and recovery; and

D. Ensuring disability care and support services do address needs, and that they promote social and economic participation.

A. Reducing the prevalence of acquired brain injury

- Brain injury is mainly preventable.

- By contrast, there are **no** health and disability prevention strategies in place in Western Australia to systematically reduce the incidence of acquired brain injury.

- The rate of incidence of acquired brain injury may be as high as 377 per 100,000 per year[2], and the incidence rate of some brain injuries leading to hospitalisation are much higher for Indigenous people[3].

- Around 1 in 45 West Australians (43,270) have an activity or participation restriction due to disability from an ABI. Of this group an estimated 15,750 people have a severe or core activity limitation, with two thirds under the age of 65.

- The prevalence of ABI in Aboriginal communities is considered to be higher than it is for the Non-Indigenous population, particularly with respect to catastrophic brain injury[4] and brain injury acquired through substance use[5]

- People with an ABI disability tend to have needs that are more complex than the average person with a disability[6] due to the high prevalence of co-existing health problems and/or disabilities, and high risks in the key social determinants of health and well being, including substance use, imprisonment, homelessness and service fragmentation.

- For example, of the group under 65, the majority of people living with ABI have associated disabilities and/or debilitating health conditions, including a prevalence of:
  - 80% - physical conditions such as a neurological, cardiovascular or respiratory conditions, cerebral palsy, and arthritis; a
  - 42% - psychiatric disability;
  - 39% - sensory/speech disability; and/or an
  - 29% - intellectual disability.[7]

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[2] Fotune, N., Wen, X., (1999), The definition, incidence and prevalence of acquired brain injury in Australia, Australian Institute of Health and Welfare

[3] Jamieson, L.M., Harrison, J.E., Berry, J.G., (2008). Hospitalised head injury due to assault among Indigenous and Non-indigenous Australians July 1999-June 2005., MJA 188,pp.576-9.

[4] Pers. Communication 18/2/2010, Dr Rina Cercarelli, previous Director, Injury Research Centre, University of Western Australia.

[5] Pers. Communication 4/3/2010, Associate Professor Edward Wilkes, Chairperson, National Indigenous Drug and Alcohol Committee.

[6] AIHW, Bulletin 55, December 2007, pp.1-5.

[7] Ibid; pp 5-9

- While the prevalence of substance induced brain injury has not yet been accurately identified in Australia; the overseas figures collated by Brain Injury Australia[8] suggest that 'of those people who experience traumatic brain injury 68% have a history of substance misuse[9]; 14% develop an alcohol and drug problem after a head injury[10] and 60-80% of clients in alcohol treatment will show some form of cognitive impairment'[11].

- Studies of prisoners in the criminal justice system indicate that with between 25-87% of inmates have an acquired brain injury[12]

Recommendation:

That the National Disability Insurance Scheme, or similar scheme, established pursuant to the Inquiry, be designed to have, as a risk management and cost saving imperative, an interest in the development and implementation of a comprehensive approach to brain injury prevention.

B. Providing a comprehensive early intervention approach

- The literature on rehabilitation and recovery is conclusive - people with acquired brain injury who receive an early assessment and diagnosis have a better long term outcomes than people who are not assessed, and who do not have an early diagnosis.

- In practice, people who acquire injuries through trauma, catastrophe and substance use are not routinely screened for brain injury. As a result, many people with an undiagnosed brain injury end up in crisis, in mental health institutions, in prison or on the streets – homeless:

> People are often not assessed for an acquired brain injury. For example after a car crash or a fight the people involved can seem fine at the time, and it may not be apparent that they have since lost cognitive function. There are examples of people coming out of comas, they leave hospital, they seem quite well. No one thinks there is a problem, the things happen – a marriage fails for example. It may take years for family members or the person to realise that their

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[8] Brain Injury Australia, n.d., *Statistics: Acquired Brain Injury*., Fact Sheet 7.

[9] Miller, N.S. (1995) Diagnosis and treatment of addictions in traumatic brain injury, Alcoholism Treatment Quarterly, 15(3), 14-30.

[10] Kreutzer, J.S., Doherty, K.R., Harris, J.A., J.A., Zasler, N.D.. (1990). *Alcohol use among persons with traumatic brain injury*. Journal of Head Trauma Rehabilitation, 5, pp.9-20.

[11] Parson, O.a. (1987). *Do neuropsychological deficits predict alcoholic's treatment course and posttreatment recover*? In O.A. Parsons, N. Butters, and P.E. Nation (Eds.), *Neuropsychology of Alcoholism: Implications for Diagnosis and Treatment*)pp. 273 – 90). New York: Guilford Press.

[12] Schofield, P.W., Butler, T.G., Hollis, S.J., Smith, N.E., Lee,S.J., Kelso, W.M., *Neuropsychiatric correlates of traumatic brain injury (TBI) among Australian Prison Inmates*. NSW. http://www.informawolrd.com/smpp/ downloaded 8/3/2010;
Department of Health & Human Services USA (n.d) *Traumatic Brain Injury in Prisons and Jails: An unrecognised problem*. CDC Fact Sheet.

> personality and other cognitive changes were due to past, undiagnosed, damage to the brain. (SSI – GP20072010)

- As people with acquired brain injury often have complex needs, and can have challenging behaviours, they often fall through the gaps in service delivery, and so become subject to institutional bias, where a lot of money and attention is perversely given, in goal, by homelessness services or in the morgue; rather than on systems and processes that will support rehabilitation:

> X1 – you know with a mental health condition, you can tick that box. If you don't have a mental health condition, you have a brain injury (instead), you can't tick that box, then there's no where for people to go. In the courts we have the Salvation Army, a mental health nurse, and we have the client with the Aboriginal Legal Service in court. And we're all standing there saying .. where can this person go? We've got a repeat offender, who has presented in court once a week now, since late last year. Now the police know who this person is. This person is a classic example of someone who does not have a mental illness. He's suffered a brain injury, yeah they've acknowledged that. It's compounded by substance abuse. But we can't take him to a hospital order, we can't make an order through the court to get him back on whatever medication he needs. All that sort of thing. So what happens is we deal with the matter. S/he receives a penalty, and is then released to go back into the community where there is nothing there for him/her. Now there must be something there that we must be missing something. It's disappointing because we know he needs help. We know it's not his fault, but where does he go? But because he does not tick these boxes, we're sort of at our wits end now.
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> X2 – I have been in that circumstance with someone with an intellectual disability with a mental health problem, and you go to the mental health people; and they say sorry guys he's got a disability, you have to go to the disability people… an on it goes…it's that box ticking thing that stuffs it … I'm sure part of that's in prevention. If we can have a system that's a bit more holistic, and we don't have to put people in boxes then we can have that kind of issue addressed..
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> X1 – Yes. It's not just a concern for our ALS, for our organization, or for myself, it's for everyone. I'm able to have conversations with the magistrate, and he's the same, saying 'what can we do'? (FG – 05082010)

- The garnering of medical evidence for an acquired brain injury can be difficult. There are those sent for a neurological assessment who have had to wait for six months, some have had to wait for up to two years. Some assessments are free, other cost at $200 or more. For many people this is not affordable.

- Assessment tools used by disability services and the Disability Support Pension and job capacity assessors are not suitably tailored to the assessment of cognitive disability, therefore many people with serious cognitive disabilities fall through the gaps as they are do not meet the eligibility criteria for income support, disability employment services and disability support services.

- As an aspect of cognitive disability is an incapacity to organise daily affairs, medical evidence required for an assessment is frequently lost by people with acquired brain injuries. Such people also have difficulty obtaining an accurate assessment as they often do not have an insight into the extent of their disability. In this case they often report to assessors that they have a capacity to live in the community without support, when in fact this is not the case.

Recommendations:

That the National Disability Insurance Scheme, or similar scheme, established pursuant to the Inquiry be designed to have, as a risk management and cost (human and financial) saving imperative, an interest in the development and implementation of a comprehensive approach to early intervention approach, with the following features:

- early comprehensive (for all post traumatic and catastrophic injuries, and substance syndrome cases), brain injury assessment that are timely, reliable and kept on an electronic data base;

- assessment of disability support and care services based on self assessment, contemporary cognitive function assessments and medical evidence;

- care coordination;

- family support from the acute early post injury phase; and a,

- rapid response, crisis intervention capacity; coupled with

- inter-agency (across health, disability & mental health sectors) care protocols, particularly for people with mental illness/ABI dual diagnosis;

- prison diversion schemes to reduce the incidence of incarceration; the

- provision of affordable housing; and

- acquired brain injury complex needs research and advocacy to identify and address systemic barriers, and promote best practice based on close and ongoing collaboration between institutions and relevant community based organisations.

C. Promoting best practice pathways to rehabilitation

- Some models of care to facilitate pathways to rehabilitation and recovery for people with acquired brain injury in Western Australia are under development.

- Services to address the disabling effects of acquired brain injury and associated problems tend to be undeveloped or in short supply, and there are problems associated with a lack of service continuity and coordination[13].

- People who are discharged from hospital are often sent home with their parents or partners, and then they and their families are not provided with the information and services needed to facilitate rehabilitation or support, nor counselling to help with grief, loss and isolation. This problem is particularly serious for people who are non-compensable under the WA fault insurance scheme.

- There is a significant shortage of physiotherapy and speech therapy services in the Perth metropolitan area, and in most rural and remote areas there are none.

- Disability and aged care support workers do not tend to know how to provide effective support and rehabilitation services to people with acquired brain injury. This is a particularly serious problem in rural, remote and regional areas.

- Workers in the disability and aged care sectors, where Aboriginal people can be in long term residential care, tend not to know how to work effectively with people with acquired brain injury nor how to provide culturally secure services,

- An approach based on evidence about what constitutes best practice pathways to rehabilitation and recovery has not been developed across the sectors that people with acquired brain injuries and their families encounter, namely the health, mental health and disability sectors, in Western Australia

- There is anecdotal evidence that the current fault insurance scheme in Western Australia may at times be a perverse incentive; as it is not in the interests of the individual nor their service to facilitate an early pathway to rehabilitation and recovery - because if the person gets better, the amount of

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[13] Bulsara, C., Cuesta-Briand, B., Morrin, R., McKenzie, A., (2010) *Evaluating the costs, accessibility and availability of services for those with a catastrophic injury in WA*. Australian Centre for Economic Research on Health and Centre for Health Services Research (unpublished – to be released, confidential draft).

compensation he or she may win could be less than if the person's condition were to stay the same or deteriorate.

Recommendations:

- That the National Disability Insurance Scheme, or similar scheme, established pursuant to the Inquiry be designed to commission research to identify inter-sectoral (health, mental health, disability) best practice pathways to rehabilitation and recovery; and to:
  - To fund models of care designed on the best practice/s so identified;
  - Assertively redress the shortage of qualified physiotherapists and speech therapists, particularly in regional areas;
  - Address gaps in service delivery;
  - Identify training needs and establish a comprehensive national training programme for disability and aged care working in the delivery of effective rehabilitation and recovery services.
  - In the event that the National Disability Insurance Scheme, or similar scheme is not established in Australia, then a no fault insurance scheme similar to the model in Victoria be established in Western Australia.
  - That systemic advocacy services are funded to: promote the development and implementation of best practice pathways to rehabilitation and recovery; and, the establishment of a no fault insurance scheme in Western Australia.

D. Ensuring disability care and support services address needs, and promote social and economic participation.

The principles of the Disability Service Standards and its associated quality management system should be retained. As the current system does not focus on early intervention, there are perverse incentives in place for people to become more disabled over time. When the individual is seriously disabled, by which time he or she is usually also in crisis, there can be access to the disability support services that are required.

By this time, many people with acquired brain injury tend to have either lost their family supports, or the family is isolated and living in poverty. In the course of caring, parents or other primary carers over time exhaust their natural support networks, and often become unemployed.

Given the broad range of disability and community participation needs of people with acquired brain injury and carers, the following service models are recommended:

- **Care coordination** The model of Local Area Coordination in Western Australia is recommended as this provides a relationship-based approach to the coordination of services across government sectors and non-government services.

  For Aboriginal people, it is recommended that care coordination services are provided by professionally trained Aboriginal personnel, and/or located in Aboriginal controlled health or other Aboriginal community organizations.

  It may be useful to embed a local area coordination model with disability employment services; as evidence-based vocational rehabilitation models in mental health suggest that service integration is key to successful employment outcomes.[14]

  It is imperative that the model of coordination has a capacity to work effectively with respect to people with complex needs, particularly for people with a dual diagnosis of an acquired brain injury and mental illness.

- **Person-centred planning and service delivery:** The dreams and decisions of people with acquired brain injury and their families should direct service delivery.

  > In the new scheme, what needs to be focussed on? When people first are initially injured, to hear what is being said by them, and also being able to hear from the other side, from people who have had injuries for years.
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  > The services need to be based on what people say is important. And also you can get the input from the carers, families. If it was me, it would be based on so much on what the brain injured person says, because people don't realise but usually cognition might be affected, the speech or whatever, but the intellect usually remains intact. People's memory loss - that's a big one. But I was fortunate, I always had to have a good memory.
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  > If I had a say, like the scheme to initially hear from the person, and also hear from their families … then decide what the discrepancies are between listening to the person and listening to the carer or family. Because with ABI, we tend to focus so much on self, there's ..

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[14] Waghorn, G, Collister, L., Killackey, E, Sherring, J., Challenges to implementing evidence-based employment services in Australia. Journal of Vocational Rehabilitation. Vol 27, No.1/2007.

> a big part of our life is self preservation, one forgets about all of the perimeter people that we need (HH – 28072010) .

- **Family Support:** Family support workers should go in early to support the family, to help prevent the loss of social support networks and the employment of family members who are carers. The Disability Service Commission's program 'Intensive Family Support' is an ideal service model in this regard.

  Aboriginal liaison officers should be made available to Aboriginal families in hospital and post discharge.

  The provision of support and care coordination services to Aboriginal families should take the socio-economic disadvantage and poor health status of Aboriginal families into account. There should not be an assumption that because families are large and extended they do not require as much support as do small nuclear families.

- **Community Development, and Capacity Building:** People with disabilities should have opportunities to have a say about micro and macro infrastructure development priorities (from, for example, pathway ramps and services to transport systems).

  Services should be developed in accordance with the ground up participation of people with acquired brain injury in decisions that affect their lives.

  A priority is the need to ensure people have access to affordable transport. The public transport system is generally hard to navigate in the Perth metropolitan area, and taxis are expensive – even when subsidised with a taxi voucher.

  Another priority for people with acquired brain injury is to have opportunities to socialise and engage in activities with other people with acquired brain injury, as well as in mainstream community activities. People learn a lot about day living rehabilitation from each other. Support groups can address the tremendous social isolation that people with acquired brain injury experience.

  > People need to connect with other people with brain injury, definitely. There should be other activities that people with brain injury can do. We, the ones with the head injuries, learn so much from each other, things that the OTs don't tell you. Like leaving notes around the house, notes to remember to lock the house up, to put the rubbish out… I remember and that lovely woman – who showed me her way of reminding herself about the washing. Little things like that, they help so much. There needs to be a community-based program of activities for people with brain injury, different things to do, like there used to be. Where the new ones coming out of hospital can see there is hope, just like I did (SSI - AH20072010)

4.0 Governance and administrative arrangements for the Scheme

Given that people with acquired brain injury are characterised by the complexity of their needs, the governance system of the scheme should make provision for the inter-sectoral coordination of post discharge pathways to rehabilitation and disability care and support:

> MW – I think what's needed is for government to say to a particular agency – "this will be your responsibility" . Because at the moment there are gaps and holes in the system that allows organizations to just buck slide if you like. So, someone with a head injury – we don't service them. They must meet this certain criteria .. if they don't … it's so tightly controlled it needs the government to say.. this will need to be dealt with by your department, and we will give you the resources to do that. At the moment, the fact that people can be shoved in all directions means that people do not get any kind of service at all. If an organization, say a mental health nurse can say we don't treat that condition, and with an ABI you can go to a number of places … What needs to happen is government needs to say – this needs to happen. Until we get that we'll keep on having this kind of dance. Whether it's a health professional, or someone else, saying that person does not neatly fit the criteria we provide services for.. (FG 05082010)

This may be a single partnership instrument, such as a Memorandum of Understanding, or other arrangement to ensure responsibility is held with a department, with, for example, disability services in a lead role with health, mental health, alcohol and other drugs, housing, alternatives to employment and employment, education (pre-primary to tertiary), justice/corrections, transport and Centrelink.

This should be established with a mandate to coordinate services around the client, and to ensure the efficient and effective transition of clients, particularly those with complex needs, between departmental and sectoral silos. This would reduce the extent of problems and costs where vulnerable individuals fall through the gaps between one service system and another.

The governance model proposed by DANA in its submission to the Productivity Commission Inquiry into disability care and support is supported.