Headwest

Disability Care and Support

Productivity Commission Draft Report

SUBMISSION

Headwest is a community based organisation providing an individual and systemic advocacy service to people with an Acquired Brain Injury (ABI) and their families. Headwest is located in Perth, Western Australia and is funded by the Disability Services Commission.

Headwest enthusiastically commends the Productivity Commission on the Report's scope, vision and intention for Australians with severe or profound disability and their family and supporters.

Headwest has previously said 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.

Comments specific to the Draft Report

Assessment

Assessment of eligibility and need is widely acknowledged as one of the greatest challenges for the scheme, both in implementation and into the future. People with an acquired brain injury have traditionally been dealt with poorly by assessment systems that have been oriented more towards physical injury and intellectual impairment assessment. Some people with an ABI can have an 'invisible' disability where it is damage to cognitive function that causes their reduced capacity to participate in life on the same terms as a person without an ABI. Simple functions of memory, thinking and communication are critical to daily life and are often impaired as a result of damage to the brain. Assessment of the impact of these cognitive problems needs to be careful and considered. Self-report by people still coming to terms with the dramatic losses from an ABI can be unrealistic and objective assessment is vital.

> 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.
>
> *(Anecdotal evidence provided by a person with ABI in consultation with Headwest regarding the NDIS)*

Extensive neuropsychological assessments are expensive but are vital for many people with an ABI. The cost of this assessment should be included in the scheme(s) to ensure that people are comprehensively assessed and are able to draw upon this assessment when accessing services or are in the justice system. Such assessments along with relevant medical records should be kept securely on a national database to efficiently provide information as required by and for individuals.

> 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.
>
> *(Anecdotal evidence provided by a person with ABI in consultation with Headwest regarding the NDIS)*

Headwest is supportive of a scheme that, when addressing the needs of a person with an ABI, considers the long term care pathways that should be available to each person with an ABI that have unique and varied needs and levels of support required throughout their lives. Their life is often a journey of recovery and hope that they will regain some lost function and the scheme should support these aspirations so that services such as physio and speech therapy along with other rehabilitative tools are available and easily accessible through the scheme throughout a person's life journey of recovery.

The need for care and support for a person with an ABI may be episodic and therefore any scheme must take into account the nature and need of people with this disability.

Eligibility

Headwest is concerned that many of its constituents would not be covered by either scheme as people with mild or medium disabilities are not eligible. This is an issue for many people with an ABI as upon diagnosis many injuries that cause mild to medium disability will often progress and other associated issues arise in a term of person's life which may significantly impair their enjoyment of life and ability to fulfil their potential. These people would struggle if they were required to try and access support under the scheme(s) in a period of time after the initial diagnosis.

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

(Anecdotal evidence provided by a health worker in consultation with Headwest regarding the NDIS)

Trialing in every state is critical

It is the view of Headwest that the NDIS trialing should occur in every state and territory in the country. This allows for early identification of challenges in each unique jurisdiction and the management of these progressively, by the NDIA and the local interested parties. Trialing in a lone state only risks the institution of another variation in the inequities across the country that the NDIS is intended to address.

A significant argument for trialing in all states is a political one, where electoral and political 'buy-in' is vital to the success of the scheme and may be compromised if there is delay in the introduction of the systems and concepts in states not engaged early. Every opportunity to foster bi-partisanship should be taken.

Implementation, including WA's unique funding and geographical features

The people of Western Australia are scattered throughout a vast and isolated state and suffer due to the lack of adequate health, accommodation and social supports if located in a rural or remote location.
For Aboriginal people of Western Australia, who have a high incidence of Acquired Brain Injury, many live away from the capital city and main towns and are often ‘lost to follow up’ upon release from hospital due to being unable to travel easily for rehabilitation which results in an enormous loss at all levels of life and an added pressure on family who may be under financial stress or suffering poverty.

For this reason it is imperative that trialing occur in and around various states and territories so that the unique obstacles for the most vulnerable people are addressed and adequately met.

Prevention education and safety initiatives

The NDIA will become a valuable agency in the Australian community in respect to identifying the preventable causes of harm that can lead to disability and promoting the reduction of these through national and local strategies.

Insurance agencies invariably are ‘risk adverse’ and provide incentives for people to ensure their own well being and safety. This philosophy may naturally underpin a community awareness raising about the possible risks of disability through injury in the case of ABI. Headwest is supportive of any campaign to decrease the possibility of people acquiring a brain injury.

Entitlements and Self-directed services

Headwest supports the proposed entitlements model for providing services, under a system akin to that of Medicare. We also support the capacity for self-directed arrangements for those with the interest and capacity to manage the funds that would otherwise be made available to them based upon their identified need. People with an Acquired Brain Injury which has caused cognitive impairments are highly unlikely to be able to elect for self-direction without significant assistance.

> 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.

(Anecdotal evidence provided by a person with ABI in consultation with Headwest regarding the NDIS)

> 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.

(Anecdotal evidence provided by a health worker in consultation with Headwest regarding the NDIS)

Mental health consumers and access to the NDIS

People with an Acquired Brain Injury frequently experience mental health issues, including significant mental illness. Advocates find that people with an ABI and a mental illness are often excluded from services on the basis of questions about whether it is their ABI or mental illness that is their 'primary' condition. This artificial bisection of a person's entitlement and need is damaging and unhelpful. There is a risk that the NDIS will institutionalise this discrimination in its application of policies and criteria relating to eligibility. Consultation with the ABI and mental health consumer communities will be needed to test some of the assumptions underlying the exclusion of mental illness disability from the scheme.

> 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..

(Anecdotal evidence provided by a person who advocates on behalf of people with ABI in consultation with Headwest regarding the NDIS)

For people with a dual diagnosis or complex need that have an ABI and a mental health care issue, accessing support in the health sector is extremely difficult. As in reform for homelessness there should be a ‘no wrong door’ policy so that an individual should not have to navigate a complex system in order to get support when they need it most. In the area of mental health and well being for people with an ABI, there should be an assumption and provision for mental health care services being provided from the point of diagnosis as an early intervention and preventative measure so that like the mental health care plans currently available through Medicare, people with ABI are provided with 12 free consultations with a mental health care provider of their choice as part of their treatment plan.

Rehabilitation/Habitation services

Headwest assumes that the majority of its constituents would be covered under the NIIS in which case they would receive rehabilitation/habitation services however we are concerned that these same services will not be covered under the NDIS and would ask the Productivity Commission to reconsider this exclusion from services available as there are currently no ‘slow steam’ rehabilitation services currently provided by the health sector.

Information requests

Chapter 4

The Commission seeks feedback on the arrangements that should apply in relation to higher electricity costs that are unavoidable and arise for some people with disabilities.

Many people with ABI, dependent upon the exact nature of their brain injury, are unable to self regulate their core temperature and many people experience a higher body temperature. The result is the need to have air-conditioning and cooling to moderate their body temperature which can be an expensive life necessity. This is an expense that may have not existed to the same extent prior to one’s injury making this a need that has arisen due to a disability.

The NDIS should assist people with needs that arise from their disability but not as an income support and should be flexible enough to respond effectively to an individual’s needs.

Chapter 8

The Commission seeks further feedback on the effectiveness of monitoring instruments and any others that could potentially be used to assist oversight of the disability sector.

It is essential that the reform be towards providing a very good quality service and one that is shared by all Australians regardless of where they live. The Disability Services Standards and National Quality Framework for Disability Services should be implemented for every disability service provider including government, non-government, not for profit and for profit agencies.

Monitoring instruments must be independent of government and the NDA, a taskforce and watchdog committee in each state made up of ‘official visitors’ with representatives from the major agencies and stakeholders including consumers and carers could be an effective monitor of the scheme and must effectively represent the groups affected by the scheme.

Chapter 16

The National Injury Insurance Scheme (NIIS) should exist alongside the NDIS so that there is consistency across schemes and for people who may initially fall under the NIIS then later under the NDIS.

The schemes should be trialled and implemented as separate schemes but there should be very clear pathways for long-term care in both schemes.

Other Comments

Advocacy

As an advocacy agency Headwest is both disappointed and concerned that the important role of advocacy is not included in the proposed model. With a model based on self-directed care there is a great risk for people who do not have capacity to ensure that they are getting value for money from the services and supports they are buying. There must be within the model a very clearly identified process for seeking support and redress through advocacy support. Similar to the principle at the heart of self directed funding, good advocacy is about supporting the person to be confident to advocate for themselves but often this is not possible and all people's rights to quality services and support must be upheld.

Advocacy agencies would assist individuals by providing independent advice in selecting the most appropriate services and would then of course be in a position to monitor service providers and ensure individuals' right to the best possible care and support.