



## **Submission**

**To: Community Development and Justice Standing Committee**

**Re: Inquiry into Accommodation and Intensive Family Support  
Funding for People with Disabilities**

**January 2014**

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## Headwest

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Headwest provides a specialist advocacy, training and awareness service for people living with an Acquired Brain Injury (ABI), their families and Carers in Western Australia. Our primary objective is to ensure that all people living with an ABI have access to the support and resources they need to optimise their social and economic participation in a welcoming community.

Based on current population data, there are 57,440 individuals living with an ABI in Western Australia, accounting for 2.3% of the population<sup>1</sup>. Acquired brain injury is a leading cause of permanent disability among individuals<sup>2</sup>. It is our aim to strengthen the capacity of all people living with ABI and their families to have a voice.

This submission was developed by Headwest based on our work with individuals and families living with ABI. Evidence of current circumstances and recommendations for change is representative of the lived experience of acquiring a disability, and the process of obtaining funding, support and assistance that should be a rightful entitlement.

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<sup>1</sup> Australian Bureau of Statistics. Survey of Disability, Ageing and Carers: People with a disability with requested conditions. 2009.

<sup>2</sup> Centers for Disease Control and Prevention. National Center for Health Statistics. Health Data Interactive. 2009 [27 Apr 2013]; Available from: [www.cdc.gov/nchs/hdi.htm](http://www.cdc.gov/nchs/hdi.htm).

## Introduction

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Headwest welcomes the opportunity to make a submission into this inquiry. We recognise the inefficiencies and inconsistencies associated with the current funding application process, and want to ensure that these are adequately and justly addressed.

Recent evaluations of the National Disability Insurance Scheme (NDIS) launch sites have reported that the level of need of individuals with disabilities and their families to be much higher than originally anticipated. This highlights the necessity of having an accurate understanding of these needs in order to be able to appropriately address them, and to be able to evaluate the outcomes associated with this. While the NDIS promises that the needs of all people will be met<sup>3</sup>, it could be up to six years before the Scheme is fully implemented. Until this time, there needs to be an accessible and equitable funding application process to ensure individuals with disabilities and their families have the support, service provision and quality of life that is their right.

This submission responds to the three key areas identified for the inquiry from the perspectives of the individuals themselves. This phenomenological approach ensures that the conveyed information is truly reflective of the adequacy of the current process, the level of unmet need and the nature and extent of planning that will be required to meet increasing demand for support services.

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<sup>3</sup> National Disability Insurance Agency. National Disability Insurance Scheme: About Us. 2013; Available from: <http://www.ndis.gov.au/about-us>.

# Terms of Reference

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## 1. The adequacy of current processes for determining funding support for people with disabilities who live with their families:

According to the 2013 Disability Support Funding Bulletin, 1911 people applied for individualised funding through the Combine Application Process (CAP) and other individual funding streams<sup>4</sup>. The bulletin reports that two thirds of processed applications will be unfunded, and carried over the next CAP round. While a person may not receive their funding request immediately, *most* applicants access alternative services while waiting for subsequent rounds to be processed.

*‘Tom being ineligible for any compensation as a 16 year old person catastrophically injured is a sickening reality for us, leaving me without a lot of hope....’*

- Parent

## Transparency of the process

The audit conducted in 2007 by the Auditor General outlined that the Commission’s (Disability Services Commission) funding process was not an open process, the assessment process lacked accountability and that unsuccessful applicants are provided with no specific feedback<sup>5</sup>.

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<sup>4</sup> Disability Services Commission. Disability Support Funding Bulletin. Issue 2, Sept. 2013. 2013.

<sup>5</sup> Auditor General for Western Australia. Auditor General Report: Performance Examination. A Helping Hand: Home-based Services in Western Australia. 2007.

Whilst modifications have since been made to simplify the application process, these specific outcomes remain unchanged.

*‘When seeking feedback about the submissions, I was told that DSC has too many applicants for the funds available. This limited feedback is not helpful, particularly when government agencies should have transparent and accountable decision making’*

- Parent, Sept. 2013

In accordance with the Auditor General's evaluation, there is *‘an air of secrecy that is out of step with modern public administration’*. This statement from 2007 still resonates today. The CAP specific funding bulletins reporting outcomes of the previous financial year are no longer publically available. Funding opening, closing and allocation dates are no longer released. To our knowledge, there is no readily available source relating to appropriate funding, reporting or feedback guidelines for disability service users. This is of exceptional concern, given that enabling access to information for individuals with disabilities is a DSC priority<sup>6</sup>.

### **CAP Application Form**

Current CAP applications are assessed solely on the basis of a written form. There are no rules or regulations regarding who completes this form. Substantial cognitive impairments are a well-recognised outcome in individuals with ABI. These individuals have significant difficulties with attention and concentration, memory and executive functioning skills – all elements required to complete an extensive written application.

*‘Each CAP submission takes many hours of work including consulting with relevant service providers.’*

- Parent

The CAP should be a process that empowers families. Applicants are applying for support to ensure their family can stay together during a time of utmost hardship, whilst ensuring the highest quality of life for the individual

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<sup>6</sup> Government of Western Australia: Disability Services Commission. Understanding Disability: Accessing Information. 2013 [24 Jan 2014]; Available from: [http://www.disability.wa.gov.au/understanding-disability1/understanding-disability/accessibility/accessible\\_information/](http://www.disability.wa.gov.au/understanding-disability1/understanding-disability/accessibility/accessible_information/).

requiring funding. Brain injury has profound effects on the entire family unit, with family strain, depression, psychological distress, and burden well documented<sup>7 8</sup>. Supporting family cohesion and connectedness is an important priority for all concerned when working with individuals with an ABI and their families.

### **Evidence of eligibility**

For individuals with an ABI, providing evidence of disability is a significant barrier to completing and obtaining funding via the CAP. In order to do this, individuals require access to a neuropsychological assessment (a scientifically rigorous evaluation of various areas of cognitive-behavioral functioning, including; perceptual, sensory and motor functions, concentration and attention, memory, planning and organisation, emotions, personality and behavior, language, hearing and sight, problem solving, and study skills). This can only be done through the private sector, so individuals themselves must fund access to such specialised services, of which there can be lengthy wait times for an appointment. However, neuropsychology specialists will not complete an assessment of an individual for eligibility for the Commission. This results in advocates attempting to organise evidence of eligibility in a way that favours the individuals, but is not favorable to the system as a whole.

### **Recommendations**

1. Increased access to knowledge and information. The assessment criteria, process and priorities for CAP funding need to be made clear in a way that can be understood by service providers, primary carers and individuals with disabilities.
2. The move towards an outcomes based needs assessment and/or support for person-centred, individualised planning. This may include interviews or an opportunity for individuals to express and communicate their needs in a way that is suitable for them.
3. Quality monitoring, accountability and a culture of client-focused improvement and assessment. This should include follow-up outcomes of how the funding has affected each individual and family to provide feedback into future rounds of funding allocation.

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<sup>7</sup>Kreutzer JS, Gervasio A, Camplair P. Primary caregivers' psychological status and family functioning after traumatic brain injury. *Brain Injury*. 1994;8(3):197-210.

<sup>8</sup> Kreutzer JS, Gervasio A, Camplair P. Primary caregivers' psychological status and family functioning after traumatic brain injury. *Brain Injury*. 1994;8(3):197-210.

## **2. The level of unmet need:**

### **The CAP and unmet need**

The level of unmet need refers to the extent of personal hardship and unrealised potential in people's lives. Unsuccessful CAP applications should not be a global indicator of unmet need, given that many individuals and families are not aware of this option, do not have access to a Local Area Coordinator or are unable to complete the process due to a variety of reasons.

In Western Australia, there is a lack of a true understanding of the level of unmet need in individuals with disabilities and their families. It is essential we have an accurate understanding of this to enable the appropriate provision of services and service evaluation. We know from our work with individuals with disabilities and their families that the level of unmet need in WA remains high. However, it is becoming increasingly harder to identify the extent and magnitude of these needs when bulletins are no longer published from funding rounds, the range data is limited and little information is known about individuals (and their families) not registered with the DSC.

### **Coping versus planning**

The nature of the CAP does not support future planning for individuals with disabilities and their families. CAP funding is awarded based on evidence of the need of one application outweighing the need of another. When considering age-appropriate life stages such as moving out of home, extensive financial planning needs to be considered. For individuals with a disability, there is even greater consideration required, having to factor in out-of-home assistance for self-care, activities of daily living and community participation. However, using a needs-based approach, an application such as this would result in significant delay before achieving funding, as this would not be considered an application of crisis. This makes planning for the future extremely difficult for those caring for a family member with a disability.

*'This is not how I had envisaged [how] his life and our lives would pan out'.*

- Parent



People with disabilities have the right to live in the community, with choices equal to others, and experience full inclusion and participation in the community<sup>9</sup>.

*'I acknowledge that you cannot change our personal circumstances but would urge you to do whatever you can to improve the current limitations within our system.'*

- Parent

### **Services for transition-age youth**

In Australia, 9% of all youth aged 15–25 years (2.8 million individuals) have some level of disability, with approximately 60,000 of this group having a significant disability that requires assistance with essential activities such as living skills, self-care and mobility<sup>10</sup>. In Western Australia, there is a severe deficit in service provision for young people aged 16-18, the age where adolescents transition out of school and into adulthood. In an acute instance, Princess Margaret Hospital will very rarely admit a 16 year old, thus these individuals then have no choice but to be treated through the adult system.

*'...was sent to Shenton Park where we were all forced to comply with this adult system which was often inflexible and not sensitive to his needs as a minor.'*

- Parent

This transition age is further complicated by the capacity of organisations to effectively accommodate the needs of young adults with ABI.

*'...was exposed to some aggressive and violent behavior by some patients...resulting in [adolescent] feeling scared and unsafe...'*

- Parent

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<sup>9</sup> United Nations. Convention on the rights of persons with disabilities. New York: United Nations; 2006.

<sup>10</sup> Begg S, Vos T, Barker B, Stevenson C, Stanley L, Lopez A. The burden of disease and injury in Australia 2003. PHE 82. Canberra: Australian Institute for Health and Welfare; 2007. 2009.

Currently, out-of-home accommodation options for younger people with ABI sees aged-care facilities as their only options. Furthermore, adolescents are often assessed and approved by an Aged Care Assessment Team to receive Extended Aged Care at Home packages. There is considerably more work that can be done in terms of policy and practice to enhance these outcomes.

*'...We were fortunate to receive an EACH package for [adolescent] when he was 17, though this is totally inappropriate for a 17 year old to receive funding for aged care...this funding is not secure and could be withdrawn at any time.'*

- Parent

### **The National Injury Insurance Scheme**

Individuals who acquire significant and catastrophic injuries represent a significant amount of unmet need. While improvements in function can and do occur within the first six months of recovery from an ABI<sup>11</sup>, significant physical, cognitive and behavioral impairments that impact on all areas of function are a long term outcome for these individuals<sup>12 13</sup>. Furthermore, the WA State Government is yet to commit to the National Injury Insurance Scheme (NIIS), individuals involved in accidents in where they are deemed to be 'at fault' currently go uncompensated. This places a significant amount of stress, hardship and burden on not only the individual, but their family and support networks.

*'...We are unable to fund this placement as [father] is in receipt of the Carers Allowance and is living in rented accommodation, while I [mother] have to reduce my employment to part time to assist in caring for [son] and still have a mortgage to pay.'*

- Parent

### **Recommendations**

1. Determining an accurate level of unmet need in WA is a critical step in ensuring future funding allocation and planning for disability services in WA. Constructing a project team to analyse existing data and develop

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<sup>11</sup> Begg S, Vos T, Barker B, Stevenson C, Stanley L, Lopez A. The burden of disease and injury in Australia 2003. PHE 82. Canberra: Australian Institute for Health and Welfare; 2007. 2009.

<sup>12</sup> Begg S, Vos T, Barker B, Stevenson C, Stanley L, Lopez A. The burden of disease and injury in Australia 2003. PHE 82. Canberra: Australian Institute for Health and Welfare; 2007. 2009.

<sup>13</sup> Begg S, Vos T, Barker B, Stevenson C, Stanley L, Lopez A. The burden of disease and injury in Australia 2003. PHE 82. Canberra: Australian Institute for Health and Welfare; 2007. 2009.

and implement a method to gain insight from individuals with disabilities state-wide will assist in creating a more accurate picture of the level of unmet need. Without this, we cannot adequately meet the needs of these individuals and families.

2. The WA government to commit to the introduction of no fault injury insurance and the implementation timeline of the NIIS.
3. Appropriate services for adolescents and young adults should be addressed as an urgent priority. The current state of service provision for this age group is severely lacking. Funding opportunities, accommodation facilities, respite care and community activities need to be developed to ensure there is opportunity for positive long term outcomes of this age group.
4. To better integrate services for the benefit of caregivers and individuals with a disability, government and non-government services and organisations need to articulate and work together, and share resources.

### **3. The nature and extent of planning required to meet increasing demand for these support services in Western Australia in the future:**

The process of ensuring that services address the needs and wants of individuals with disabilities should be a consistent process across all levels of service provision in society. From policy, to community service, to immediate supports, to the individual, planning should occur with this at the forefront of all processes.

*'Families and individuals who will follow after us need and deserve better outcomes'.*

- Parent

No one knows the situation of an individual with a disability more comprehensively than themselves. Involving consumers in research and planning supports the development of interventions that are relevant to the needs of the target group, supporting their use and ultimate success. Thus, in attempting to improve funding application processes to improve overall

outcomes, it is imperative to ensure that individuals themselves are actively consulted with regards to the assessment of their needs.

Consumer and community advisory councils, steering groups and reference groups foster linkages between government institutions and the wider community<sup>14</sup>. Furthermore, a strong overlap exists across sectors and the goals of key stakeholders have a strong overlap, and by working together we may be able to improve overall outcomes.

*'...It was not just [son] who was hit by the bus on the day of his accident; it was all of us'.*

- Parent

**End**

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<sup>14</sup> Consumer and community participation in health and medical research: A practical guide for health and medical research organisations: Telethon Institute for Child Health Research; 2012.