



**Senate Community Affairs References Committee Inquiry:**

**“Adequacy of existing residential care arrangements  
available for young people with severe physical, mental or  
intellectual disabilities in Australia”**

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**Headwest consents to this submission being published**

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## Headwest

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Headwest (the Association) provides a specialist advocacy, training and awareness service in Western Australia (WA) for people living with an Acquired Brain Injury (ABI), their families and carers. The Association's primary objective is to ensure that all people living with a disability have access to the supports and resources they need to optimise their social and economic participation in a welcoming community. Headwest is committed to facilitating solutions, driving change and building knowledge of ABI in the WA 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 Headwest's aim to strengthen the capacity of all people living with ABI and their families to have a voice.

This submission provides feedback on the adequacy of current residential care arrangements for young people with significant disabilities in Western Australia. It is based on Headwest's work with young people, and their families and carers, who have had the experience of being unable to access appropriate residential care arrangements. Individuals and families supported by Headwest have contributed to the development of this submission.

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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. [www.cdc.gov/nchs/hdi.htm](http://www.cdc.gov/nchs/hdi.htm), 2009 (accessed on 27 April 2013).

## Response to the Terms of Reference

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### **The estimated number and distribution of young people in the aged care system in Australia, and the number of young people who require care but are not currently receiving care.**

As of 30 June 2013, there were 6,376 individuals, under the age of 65, accessing permanent and respite residential aged care accommodation in Australia<sup>3</sup>. In Western Australia, there were 510 individuals younger than 65 in aged care facilities, accounting for 3.5% of people in residential aged care in the state<sup>4</sup>.

Headwest is aware of a number of individuals with disability, under the age of 65, who are waiting in hospital for appropriate accommodation to become available or report they were forced to access aged residential care, as alternative options were not available.

Currently, Headwest supports five young people who are waiting for availability of appropriate accommodation options who are currently in hospital, in a transition option or being cared for family as a short-term option. Four individuals are in an aged residential care option. All of these individuals are under the age of 65.

### **Short and long term trends in relation to the number of young people being cared for within the aged care system.**

Between 2003 and 2009, the number of young people permanently living in aged residential care settings in WA increased from 478 in 2003 to 541 in 2009<sup>5</sup>. The following two years saw a decrease, with 538 young people in aged care in 2010 and 496 in 2011<sup>6</sup>. This decrease can be partially attributed to the Younger People with Disability in Residential Aged Care (YPIRAC) initiative by the Council of Australian Governments, which saw 20 individuals in Western Australia move from residential aged care to supported disability accommodation<sup>7</sup>.

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<sup>3</sup> Australian Institute of Health and Welfare. Residential and community supplementary data. Residential Care - Table S2.10: Permanent and respite residential aged care clients, by sex and age group. <http://www.aihw.gov.au/aged-care/residential-and-community-2011-12/data/>, 2013 (accessed on 2 February 2015).

<sup>4</sup> Australian Institute of Health and Welfare. Residential and community supplementary data. Residential Care - Table S2.11: All residential aged care clients, by age group, sex and state/territory. <http://www.aihw.gov.au/aged-care/residential-and-community-2011-12/data/>, 2013 (accessed on 2 February 2015).

<sup>5</sup> Australian Institute of Health and Welfare 2012. Younger people with disability in residential aged care 2010-11: additional tables. Disability Series. Cat. No. AUS 155. Canberra: AIHW. p1.

<sup>6</sup> Ibid.

<sup>7</sup> Australian Institute of Health and Welfare 2012. Younger people with disability in residential aged care 2010-11: additional tables. Disability Series. Cat. No. AUS 155. Canberra: AIHW. p42.



As previously indicated, by June 2013 the number of young people in aged care accommodation in WA was 510<sup>8</sup>. While this shows an increase of 14 individuals from 2011 to 2013, it is difficult to ascertain, without access to current figures, whether this is an ongoing trend. Never-the-less, this increase indicates that the current strategies for transitioning young people out of aged care facilities and preventing young people entering aged residential care, are inadequate.

Discussions with individuals, families and carers, as well as anecdotal feedback from across the sector, indicates that difficulty finding appropriate and timely accommodation within current systems continues to be an issue. In addition to families who report the only option on hospital discharge was aged care, many also report difficulty finding appropriate alternatives for young people when support networks have broken down and family and friends are no longer able to provide informal supports. Headwest is aware of a family, no longer able to provide ongoing support at home for their 17 year old son, who have been advised their only option is a referral for accommodation in an aged care facility.

### **The health and support pathways available to young people with complex needs.**

There are currently insufficient health and support pathways for young people with complex needs. The health and hospital systems in WA are unable to accommodate individuals indefinitely while waiting for a suitable alternative to become available. Lack of appropriate and timely access to rehabilitation and transitional services puts additional stress on the already over-stretched health system. This further increases the pressure to discharge young people as quickly as possible. In this environment, the only option often available is through the aged care sector.

In WA, there are few hospital based rehabilitation and transitional services and even fewer non-hospital based services, such as those provided by Brightwater Care Group. Feedback from families and social workers in the health system, indicates that Brightwater is unable to meet the high demand for rehabilitation and support, to enable smooth transition from hospital to a community setting, such as living with family or living independently with assistance. Headwest currently receives contact from hospital social workers almost on a daily basis asking if there are any other alternatives for young people transitioning from hospital.

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<sup>8</sup> Australian Institute of Health and Welfare. Residential and community supplementary data. Residential Care - Table S2.11: All residential aged care clients, by age group, sex and state/territory. <http://www.aihw.gov.au/aged-care/residential-and-community-2011-12/data/>, 2013 (accessed on 2 February 2015).

Furthermore, eligibility for rehabilitation and transitional services is largely dependent on a person's potential for further improvement with additional therapy or support. Some young people with significant disabilities are considered unlikely to improve and, therefore, are unable to access these services. As the demand for accommodation options within the disability sector is high, the only alternative pathway is aged care.

Traditionally young people with disability, who are in hospital, have had difficulty accessing support through the Disability Services Commission's Local Area Coordination network. While there have been improvements in this area over recent years, some individuals and families continue to find this a barrier, particularly where further rehabilitation may result in some, often minor, improvement in skills and abilities. In these circumstances an LAC may decline to accept a person because their long-term disability status is considered unclear. Unfortunately, it is during the hospital rehabilitation phase that links with the disability sector, via LAC, to investigate options and plan for the future are vital. As previously mentioned, families and individuals often indicate they were not aware of any alternatives and therefore believed that support through the aged care system was the only option.

In Western Australia, individuals wishing to access accommodation support through the disability sector, with the exception of people in the National Disability Insurance Scheme trial sites, must apply for funding through the Combined Application Process (CAP). Applicants are prioritised based on urgency of need and funding allocated accordingly. Often young people in hospitals or nursing homes are not prioritised for CAP funding because their need is not considered sufficiently urgent. While separate funding for this cohort is regularly made available in the funding rounds, the level of funding is not sufficient to adequately address the number of young people in aged residential care. Discussions with families and young people in aged care facilities indicate that many have been applying for CAP funding for years but have not been successful because they already 'have a roof over their head'.

### **The appropriateness of the aged care system for care of young people with serious and/or permanent mental or physical disabilities.**

The aged care system is not an appropriate avenue of support for young people with significant disabilities. Firstly, the aged care system is designed to support individuals in their remaining years, and all aspects of the care, such as diet and daily activities, are structured around the elderly. The majority of people accessing support in aged care facilities (76.9 percent as of 30 June 2013) are aged 80 years and over<sup>9</sup> and their needs differ greatly from the needs of the individuals under the age of 65.

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<sup>9</sup> Australian Institute of Health and Welfare. Residential and community supplementary data. Residential Care - Table S2.10: Permanent and respite residential aged care clients, by sex and age group.



According to individuals and families supported by Headwest, lack of peer interaction has a significant impact on the health and well-being of young people in aged care facilities. The inability to mix with people of a similar age, who share similar interests, often results in feelings of loneliness and isolation. This increases the likelihood of depression and can compound the impacts of the disability. For example, an increase in challenging behaviours, mood swings and poor impulse control may result when an individual with a brain injury is socially isolated and becomes unhappy. This can be further compounded in situations where a young person shares a room with an older resident, rather than an age appropriate house-share arrangement with another person of a similar age.

Individuals, who have accessed support through aged care settings, have indicated that one of the hardest experiences was watching their older friends die. Each time this occurred it became more and more difficult to be open to establishing new friendships with other older residents. As a result, these individuals became even more socially isolated. For young people residing in an aged care setting for a considerable length of time, it is conceivable that they will experience significant loss through the deaths of older residents which may impact on their ability to establish and maintain close relationships, not only in aged residential care, but throughout their life.

Generally staff within aged care facilities have limited skills in supporting young people with disability and assisting the person to meet their needs. Knowledge around promoting independence and community inclusion, and support for the individual to participate in age-appropriate activities, is often lacking.

Young people have indicated that the design of aged care facilities does not facilitate friends coming to visit. There is limited privacy for spending time with friends, and their friends are reluctant to visit as they feel uncomfortable in the aged care setting. This reluctance can often extend to family members as well, resulting in the young person becoming increasingly isolated.

### **Alternative systems of care available in federal, state and territory jurisdictions for young people with serious and/or permanent mental, physical or intellectual disabilities.**

Within the disability sector, there is a significant unmet need for contemporary community based accommodation options for young people. Access to currently available options usually requires the individual to be successful through the Disability Services Commission's CAP process where there is no guarantee of

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<http://www.aihw.gov.au/aged-care/residential-and-community-2011-12/data/>, 2013 (accessed on 2 February 2015).

funding. As this process usually takes some time, in some cases a number of years, a young person often has no alternative but to reside in an aged care facility as an 'interim' option. Once in an aged care facility the likelihood of being prioritised for funding is significantly less.

Individuals and families, who are commonly struggling to navigate the health and rehabilitation settings at a time of considerable stress, are frequently unaware of what is available through the disability sector. Some families have indicated they were advised by medical staff that the aged care system was the only option available and they did not even think to question this advice. It wasn't until much later, after the individuals had been in aged care accommodation for a considerable period of time that the families became aware of other more age-appropriate options, through the disability sector, that could have been investigated.

### **The options, consequences and considerations of the de-institutionalisation of young people with serious and/or permanent mental, physical or intellectual disabilities.**

It is worth noting that some young people with disability initially enter an aged care facility as an interim option following discharge from hospital. This may appear appropriate, particularly when nursing care is required to assist with rehabilitation and recovery, which is usually not provided through the disability system. However, even as an interim arrangement, aged care accommodation is not able to meet the needs of young people and, therefore, is not a suitable option.

Future options must include additional rehabilitation and transitional services, which cater for the medical, therapeutic and other needs of young people. Rather than focusing so heavily on rehabilitation potential, these services need more capacity to support individuals to transition smoothly from the medical model of support to an appropriate model of community based accommodation, such as a shared living arrangement or living independently with support.

A transitional arrangement will only be successful if alternative options are available to transition into. Otherwise the issue of young people remaining in hospital longer than required will only be shifted to the transitional setting. A range of accommodation options needs to be available to cater to the wide needs and wishes of young people with disability.

The ability to be able to respond to the issue of young people in nursing homes includes commitment and resources from across the government sector. Sufficient availability of appropriate and affordable housing plays an important role in ensuring young people have accommodation that meets their needs.



Access to individualised funding will also play a role in decreasing the number of young people in aged residential care. With individualised funding, young people may be able to return to live with family for example, with support to assist the family with the caring role and enhance their capacity to provide ongoing support, without the need for 24 hour residential care.

**What Australian jurisdictions are currently doing for young people with serious and/or permanent mental, physical or intellectual disabilities, and what they intend to do differently in the future?**

Headwest is aware that the Disability Services Commission has committed funding over three years, starting in 2014 – 2015, for the purpose of increasing age-appropriate accommodation options for young people at risk of entering aged care or already reside in an aged care facility. While Headwest welcomes this strategy, the Association believes that the \$6 million identified within the State budget for this period is insufficient to significantly influence the numbers of young people in aged residential care.

**The impact of the introduction of the National Disability Insurance Scheme on the ability of young people in aged care facilities to find more appropriate accommodation.**

In Western Australia, trial sites for the Commonwealth and State versions of the NDIS have been underway since 1 July 2014. At this early stage, it is difficult to ascertain the impact of the introduction of NDIS on young people in aged care facilities. While it is hoped that the roll-out of an NDIS scheme across WA will have a significant and positive impact on the ability of young people to find more appropriate accommodation, this will depend heavily on sufficient numbers of appropriate and affordable housing options being made available within the system.

**State and territory activity in regard to the effectiveness of the Council of Australian Governments' Younger People in Residential Aged Care initiatives in improving outcomes for young people with serious and/or permanent mental, physical or intellectual disabilities, since the Commonwealth's contribution to this program has been rolled into the National Disability Agreement and subsequent developments in each jurisdiction.**

As previously mentioned the number of young people in aged residential care in WA increased from 496 in 2011 to 510 in 2013<sup>10</sup>. This coincides with, and may be linked

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<sup>10</sup> Australian Institute of Health and Welfare. Residential and community supplementary data. Residential Care - Table S2.11: All residential aged care clients, by age group, sex and state/territory.



to, the Commonwealth's contribution to the YIPRAC program being rolled into the National Disability Agreement.

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