

Accommodation for people living with disability and the NDIS

Submission to the Joint Standing Committee on the National Disability Insurance Scheme from Brightwater Care Group (Inc)

Introduction

The Brightwater Care Group is one of the largest providers of residential care in Western Australia employing more than 2,100 staff and providing care to over 2,500 Western Australians across 23 facilities located from Joondalup to Mandurah as well as a variety of community and at home care services. Although often recognised for its services to people who are ageing, Brightwater has also been providing specialist rehabilitation, transition and accommodation services to people with a neurological disability for over 20 years.

Within its suite of services Brightwater delivers a number of specialist services that support younger people with complex disability. These include:-

1. Long Stay Younger Persons Program (LSYP) – transitional support and interim accommodation for people with complex disability unable to discharge from the metropolitan hospital system

Funded by the Health Department of WA, this program developed as a result of large numbers of people under the age of 65 in metropolitan hospitals who had complex disability but were medically fit and ready for discharge. Due to the complexity of their care needs they remained as inpatients for lengthy periods whilst their carers, clinicians and service providers engage in protracted negotiations to find a suitable pathway out of acute care. This resulted in acute care beds being used as interim accommodation to the detriment of other patients needing inpatient care.

High level of care in interim accommodation within the LSYP Program allows younger disabled clients to adjust to their medical condition, optimise their physical and psychological functioning and maximise their ability to enter long-term supported accommodation or to return home with community support. During the period of interim accommodation, individuals are supported to develop a planned exit strategy to access long-term supports to meet their assessed needs.

2. Oats St Rehabilitation Program – slow stream rehabilitation in a home-like, community based residential environment

The Oats Street Program provides a residential and community based rehabilitation program for people with a diagnosis of neurological disability, due to acquired brain injury (ABI). The program has a strong focus on Cognitive Rehabilitation Therapy and goal directed individualised outcomes.

While the program aims to maximise functional ability, it also focuses on identification and development of appropriate long-term accommodation.

3. Accommodation Services for People with Huntington’s Disease – a continuum of support services for people with Huntington’s Disease including two shared community houses, Ellison and Kailis House, for people with mid and end stage presentation.

Both Ellison and Kailis House, funded by the Disability Services Commission, are part of a larger continuum of care for people with Huntington’s Disease. This continuum also supports people to live in their own homes while others may choose to live in a Brightwater residential aged care facility. The aim of the continuum is to provide people with a choice of accommodation options, enable them to plan for the future degeneration associated with the progressive nature of the disease and to be provided with support commensurate with their needs

4. Accommodation for People with Severe Disability Related to Acquired Brain Injury (Endeavour House) – shared supported living in a high care environment conducive to supporting people with brain injury who have extremely complex care and health needs.

Endeavour House supports people with an acquired brain injury whose severity of injury prevents them from effectively and spontaneously interacting with their immediate environment. All people living at Endeavour House have both high support needs requiring the availability of a multidisciplinary team and high health care needs necessitating the availability of 24 hour nursing staff. This facility is situated in the local community and aims to provide all people living there with a healthy and stimulating lifestyle.

The very nature of the programs outlined above plus the many years that Brightwater has been providing these services for means that the organisation has a comprehensive level of understanding, knowledge and expertise in supporting people with disability. Many of these services are unique to Western Australia and assist people in linking to and transitioning between the health and disability sectors.

Within the scope of services that Brightwater provides the issue of housing is a prevalent one. For some of our customers we are providing opportunities for lifetime living, while for others our connection is an interim arrangement that often includes a requirement on us as a provider to support the individual on identifying and preparing for future accommodation arrangements. This has given the organisation a unique insight into the challenges and potential opportunities in providing appropriate housing options for people with disability. Due to this experience the submission below is made up a number of concepts and challenges that we feel should be considered in the development of a housing framework for people with disability.

1. Role of Government

- 1.1. It is essential that government at all levels work together to fulfil their responsibility to create a buoyant and flexible housing sector for people with disability.
- 1.2. While it would appear to be the intention of the federal government to stimulate investment in specialist disability accommodation (SDA) from private investors it should be recognised that there is a current dearth of SDA for people with high and complex needs with nursing homes having become the only housing option for many in this group. As such, a two tiered approach is needed: urgent capital investment to alleviate the immediate problem and then a more planned forward-thinking approach. This planned approach can

be supported by evidence of numbers, diagnostic groups and care requirements as the NDIS moves towards full implementation.

- 1.3. It is also the role of government to ensure that there are long term sustainable housing solutions going forward. Areas of consideration include:
 - As an overarching requirement, all developments should include internal infrastructure that provides accessibility for people with disability. Accessibility should not just be confined to the built housing environment but should be integral to the very fabric of each and every local community.
 - The opportunity to ensure that a percentage of affordable, adaptable housing is included where possible in each new housing development. Currently there is a tendency to locate affordable housing within newer developments built on the outskirts of capital cities and major centres across each state. To offer all people with disability genuine choice and control over where they live and the type of housing that they live in, the spread of affordable adaptable housing should be across a range of urban and rural areas including more affluent and well developed suburbs and remote areas in states such as Western Australia.
 - Regardless of their location within the state all developments must take into account the logistical needs of people with disability, such as ease of access to transport, nearby shopping centres and essential services such as medical support, Centrelink and community facilities.
 - The role of local government in forming collaborative relationships with affordable housing developers around the development a diverse range of housing in keeping with the values and norms of the local community should not be underestimated. Longstanding members of a community living with a disability should not be forced into relocating to other areas due to an inability to access appropriate affordable adaptable housing in their familiar area.

2. Investment into the Sector

- 2.1. In order for there to be investment into the housing sector by a wide range of stakeholders, including people with disability themselves, families, and large housing corporations stimulation of that investment needs to be framed in such a way as to encourage that diversity. Some points to consider include:
 - 2.2. The current burden of regulation and compliance required to become and continue to be a social housing provider is a significant barrier to entry for many investors.
 - 2.3. To achieve the ultimate aim of people with disability owning their own home in areas of their choice the considerable issue of affordability for this group requires addressing. According to the ACOSS publication Poverty in Australia 2012 27.4% of people with a

disability were living in poverty in 2009-2010 compared to 12.8% for the total population.¹ While more recent figures have not yet been released, ACOSS suggests that this figure has risen in the last 5 years. Items that will need solutions include mortgage availability, low cost loan repayments and minimal deposits. For many people with disability even fulfilling the complex legal requirements and accompanying paperwork will be beyond their capability and assistance should be provided to ensure that any loan arrangements do not put them at greater risk.

- 2.4. Discrete amounts of government investment that is attached to the dwelling rather than the individual would provide some certainty and security for investors to stimulate investment in accommodation options for adults with newly acquired disability who will require immediate access to housing. As this group are new entrants to the NDIS forward planning on an individual basis will not be possible but forward planning based on numbers of people likely to acquire types of disability such as brain injury and spinal injury is possible and should be actioned.
- 2.5. There is scope to think beyond more traditional modes of investment and investors. Some ideas include:
 - Universities constructing accessible student housing for on-campus living
 - Superannuation funds providing capital investment
 - Use of social impact bonds by both private and not for profit organisations
 - The possible role of not for profit service providers as a possible source of housing investment should not be underestimated. While it would be necessary to have frank and honest communication about the possible conflict of interest inherent in such arrangements, neither is this insurmountable.
 - Likewise, while it is not ideal as a solution for lifetime accommodation, there may be a role for aged care providers to offer interim solutions for people with newly acquired disability.

3. The Limitation of Cultural Expectations

- 3.1. Often the size, shape and location of what is considered “normal” housing for people with disability is influenced by cultural perceptions of what is a home or a house. The strong emphasis on home ownership in the shape of a traditional four-by-two single storey dwelling on a quarter acre block has long been part of the Australian psyche. In Western Australia we have observed that this concept of housing and home ownership when coupled with the belief that it is always better for people with disability to either live alone or with their immediate family, influences not only the style of housing that is currently offered to people with disability but also how support funding is arranged.
- 3.2. The provision of individualised funding available through the NDIS is an exciting mechanism through which people with disability can exercise choice and control over not only their immediate living arrangements but also over future plans. Planning for current and future

¹ <http://www.acoss.org.au/poverty-2/> Accessed 18 Feb 2016

housing should be as integral to an individual's NDIS Plan as support funding with strong actions and outcomes clearly documented. This has potential to influence housing planning not only on an individual basis but also to provide an aggregated picture of future need.

3.3. Possible considerations to be built in to individual Plans may be:

- Levering off the rental market to maximise choice on style of housing and location, and offer people opportunity to trial a number of different options.
- Cooperative arrangements that can offer shared living with friends. This may enable to individual to live in comfortable and affordable housing while saving a deposit for their own home.
- Flexible rental or home ownership arrangements that enable people to move easily as life circumstances change. This will include upsizing and downsizing through out the spectrum of life.

4. Specific Issue for People with Disability

- 4.1. For all people diversity and individualisation is the key to providing a satisfactory lifestyle within the unique qualities of each human being. Many people with disability have additional challenges and considerations that will need to be factored in to each individual's housing planning. For some these challenges and considerations can be generalised across a wide spectrum of people with disability while for others there will be specific issues that need to be addressed.
- 4.2. There will be a cohort of people with disability who, due to past funding arrangements, have been forced to live in the family home or in a shared living arrangement. While many of these people may choose to continue in that arrangement others will seek opportunities to live in their own home in the community. Due to challenges in home ownership for most rental accommodation will be their main option. In our experience gained from many years of supporting people with brain injury to access rental accommodation once they are at the end of their rehabilitation journey, concerns that often have to be addressed are:
 - **Lack of rental history.** Landlords usually require evidence of rental history as well as references to determine suitability of applicant. People with disability who have never rented before do not have these and this poses a serious disadvantage in a competitive rental market.
 - **Affording items to establish the home.** Initial setup costs for people who have never lived in their own home are high. These will include rental bond, furniture, fittings, utensils and appliances and may be preclusive to those whose sole form of income is the Disability Support Pension.
 - **Understanding how to maintain a tenancy.** It cannot be assumed that all people with a disability will be able to appropriately manage a tenancy without support. Factors they will need to consider include basic property maintenance, care of the garden, relationships with neighbours, setting up and managing utilities and keeping the property in good order to meet rental inspection requirements. It should also be recognised that for some people with disability maintenance requirements due to the

- wear and tear that the property is subjected to will lead to higher than average financial outlay.
- **Re-establishing connections.** For many individuals who are moving out of the family home or changing their living circumstances a change of community will also be a consequence of that move. This will require the individual to establish new connections within a new community for essential services such as medical support, shopping, Centrelink and other community facilities.
- 4.3. Due to the remoteness and size of many Western Australian communities housing options for people living with disability who want to remain in or move back to their rural community are extremely limited. In our experience people who have newly acquired disability through trauma or disease are often faced with moving from their home community to the Perth metropolitan area. On occasions this has resulted in whole families relocating and this can be particularly distressing when it involves loss of a multigenerational connection with the community, such as when selling the family farm or, in the case of indigenous people, disconnection from their land. Housing price differentials between the Perth metropolitan area and many rural communities can also mean for many individuals and families a vast reduction in their quality of life and financial security.
- 4.4. In providing services for people with acquired neurological disability over many decades Brightwater Care Group has had the privilege of witnessing the potential for each individual to grow and change over the course of their life. Unfortunately the opportunity to utilise this ever-growing capacity to live independently is often restricted by the inflexibility of both the current funding arrangements and the limits of the housing sector. It is essential that under an NDIS funding model that will offer far more portability to the individual that the housing sector also develops to offer people the opportunity to relocate as their needs and wants change.
- 4.5. Of major concern is the extensive gap within the emergency and interim housing market. Since 2008 Brightwater Care Group has operated on behalf of the Health Department of Western Australia a transitional program for people with disability who although medically stable are unable to be discharged from the acute hospital sector to suitable accommodation. This is due both to a lack of funding for all people with disability and to a lack of suitable specialist disability accommodation. With the inception of the NDIS funding for each individual with complex disability will be guaranteed, however this still fails to address the severe housing shortage. It should be noted that at this point in time it is not uncommon for young people with complex disability to find that aged care is their only lifetime accommodation option.
- 4.6. Funding proposed under the Specialist Disability Accommodation Draft Report ascribes a calculated amount of funding that is attached to individual packages for the purpose of contributing to the cost of specialised housing for those who require it. While this system is workable for those with lifetime disability who for the most part are able to be supported to plan often years ahead for their future accommodation options, for those with newly acquired disability planning is not possible. It should be recognised that for this group the transition time between living without disability in the family home to requiring specialist disability accommodation can be measured in days, not years. Nursing homes should not be their only option. It is essential that state and federal governments allocate capital investment to a range of housing options that can provide interim living arrangements for this uniquely homeless group.

- 4.7. Experience in providing services to people living with Huntington’s Disease has reinforced to Brightwater Care Group the need to offer environments that are flexible, have multiple layers and types of functionality, provide certainty between expectations and outcomes and engenders familiarity and trust. This is in part due to the degeneration of cognitive abilities which result in an increased rigidity in thinking along side of a need to maintain as much control of their lives in the face of that degeneration as possible. Consideration should be given for both those with Huntington’s Disease and others who experience cognitive decline within the framework of their disability, for example those with younger onset dementia, for the development of mixed use environments that offer a range of accommodation options for people with and without disability and communal and community facilities.

Conclusion

Brightwater is able to offer a unique perspective on the specific challenges that face individuals with newly acquired and long term neurological disability. In our experience this group is often overlooked in planning and strategic development of frameworks that are designed to support the disability sector. While we have covered a number of concepts in the paper above we would like to take the opportunity within this conclusion to reinforce the particular challenges around offering diverse and flexible housing to a group of people who within days are transitional from living life without disability to a lifetime of requiring care and support.

This submission is made on behalf of:

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