



**Submission to
Senate Community Affairs References Committee**

**Inquiry into the adequacy of existing residential care
arrangements available for young people with severe
physical, mental or intellectual disabilities in Australia**

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About Melbourne City Mission

Melbourne City Mission is one of Victoria's oldest and largest community services organisations. Our vision is to create a fair and just community where people have equal access to opportunities and resources.

Melbourne City Mission has significant expertise in service delivery, policy and regulation in the area of Disability Services. These services:

- span the continuum of early intervention, care and respite, and community participation
- are accessible to people of all ages and life stages (we provide supports to babies just six months of age, through to older people in their 70s)
- are part of a broader, integrated service platform that includes Children's Services and Family Support, Employment, Education and Training, Housing and Homelessness, Justice Services and Aged Care.

Our particular focus in this submission is young people with disabilities who are:

- residing in residential aged care in Victoria
- have been able to exit, or avoid entry to, residential aged care through housing options created under the 'My Future My Choice' initiative in Victoria.

Melbourne City Mission's response to Term of Reference (d):

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

Melbourne City Mission's work is underpinned by a human rights framework, and has a strategic focus on capacity building and social inclusion. Our practice wisdom – informed by the needs and aspirations of people living with disability – tells us that:

- 1) Residential Aged Care is an inappropriate housing option for young people with disabilities
- 2) When young people with disabilities enter the residential aged care system, they do so because there is a critical shortage of more appropriate housing options.
- 3) The ability to exercise personal choice and control in housing is a fundamental human right for all citizens – absence of choice adversely impacts personal development/growth (for example, setting and working towards goals in which housing is a critical pathway/enabler), level of housing satisfaction, and health and wellbeing.

1) An inappropriate housing option

Melbourne City Mission notes that there are around 6,000¹ young² Australians with disabilities who are currently living in residential aged care facilities.

This includes more than 605 people under the age of 50 who are moving into facilities where the average age of residents is 83³. Their social isolation within this environment is compounded by a paucity or absence of external networks – 53 per cent of young people in residential aged care receive a visit from a friend less than once a year⁴.

Young people are usually discharged into residential aged care because there are limited community-based service models to meet their health and clinical care needs (further detail provided in the next section of this submission). However, residential aged care facilities do not usually have the resources (funding, workforce⁵, programs and/or equipment) to adequately meet the specialised needs of young people with disabilities – their primary focus is provision of support to frail elderly people.

Consequently, they have limited capacity to meet the complex physical, social and rehabilitation needs of young people.

¹ AIHW (2014), National Aged Care Data Clearinghouse

² People under the age of 65

³ AIHW (2009), *Residential aged care in Australia 2007–08*, published at <http://www.aihw.gov.au/publications/age/age-58-10709/age-58-10709.pdf>

⁴ Summer Foundation and Monash University research cited at <http://www.australianageingagenda.com.au/2011/08/25/aged-care-marginalises-the-young/>

⁵ The staff:client ratio in residential aged care tends to be lower than in disability services, and insufficient for young people with high-level support needs.

Beyond the aforementioned issue of (lack of) choice and control, the residential aged care model does not sufficiently attend to the need for:

- specialist/technical health/clinical support for young people with complex care needs⁶;
- personalised equipment/disability aids;
- staff training and development in relation to specialist care requirements;
- age-appropriate recreational and social needs and case management.

Tragically, the most common cause of permanent discharge is not to age-appropriate housing, but death or hospital⁷. Whilst degenerative conditions and cancer are likely to account for some early deaths, these conditions do not account for all deaths. Young people with very high care needs living in residential aged care are highly susceptible to secondary conditions – for example, they are at heightened risk of contracting pneumonia, which is so prevalent in the frail aged population that it is the leading cause of death in residential aged care⁸.

2) A critical shortage of more appropriate housing options

The current barriers to home ownership in Australia – and the competition for private rental, public and social housing – are well documented. The barriers to access are even greater for people with disabilities.

Going into the National Disability Insurance Scheme (NDIS) environment, the five-year Younger People in Residential Aged Care (YPIRAC) initiative established in 2006 “*made a significant difference to the lives of the people who received services but it did not create the systemic change needed to stem the flow of young people into nursing homes*”⁹. Whilst the rates have slowed, young people with disabilities continue to enter residential aged care – more than 300 people under 50 are admitted each year. The new housing and support options that were enabled by the YPIRAC are now at capacity – vacancies typically only arise when a resident dies.¹⁰

At full implementation, the NDIS will put **even more** pressure on housing supply, as more people seek to live independently. This dimension of the housing issue has been a major focus of conversation for people with disabilities, advocacy groups, policy makers, funders and service providers as the NDIS moves towards full implementation, and Melbourne City Mission notes that the release of a housing paper is imminent.

⁶ One area of specialist expertise within Melbourne City Mission is case management provided to people with an Acquired Brain Injury (ABI). We know that for this particular group of citizens, nursing homes do not have the rehabilitation focus critical to their ongoing care and, indeed, research suggests that placement of young adults in this setting can compromise the gains made in post-acute settings.

⁷ Dearn, L (2011), “*Permanent discharge*”: *Deaths of people under 50 years of age in residential aged care in Victoria*, published at

http://www.publicadvocate.vic.gov.au/file/file/Research/Articles/permanent_discharge.pdf

⁸ <http://www.racgp.org.au/your-practice/guidelines/silverbook/common-clinical-conditions/respiratory-infections-pneumonia/>

⁹ Winkler, D (2015), ‘We must keep young people out of nursing homes’, *The Age*, accessed at <http://www.theage.com.au/comment/we-must-keep-young-disabled-people-out-of-nursing-homes-20150219-13iv5g.html>

¹⁰ Ibid.

Whilst the National Disability Insurance Agency (NDIA) will have, at full scheme implementation, \$700 million per annum to assist in the provision of specialised accommodation, Melbourne City Mission notes that there are concerns amongst people with disabilities, families and carers, and advocates that young people in residential aged care – a highly marginalised group – will continue to miss out. The Summer Foundation, for example, has said that due to the current overall shortage of accessible and affordable housing, it does not expect many young people will move out of residential aged care as a result of the NDIS¹¹.

Melbourne City Mission is concerned that whilst packages will enable better provision of supports for those young people in residential aged care who participate in the NDIS (such as attendant care to meet physical/care needs), provision of these supports won't mitigate:

- the lack of choice and control that young people will have in respect of housing, and
- the adverse impacts of the residential aged care environment on physical and mental health, wellbeing, inclusion and participation.

¹¹ Ibid.

3) The importance of choice and control, and how it impacts on health and wellbeing

Melbourne City Mission works with people of all ages and life stages, including people with disabilities. Across our broad service platform, housing is a critical enabler for many of the goals that people we support identify for themselves – as the Youth Disability Advocacy Service (YDAS) has noted, *“home is the base camp for a good life ... a place for the quiet enjoyment of one’s personal and private space with friends, intimates and neighbours”*¹², and a launch pad for participation (from recreation and cultural activities through to education and work).

YDAS research¹³ into the needs, aspirations and expectations of young people with disabilities has shown that *“individuals want to have a menu to choose from that allows them to pick and combine different elements that match their needs and aspirations. They do not want to be locked into a particular house/room with nowhere else to go. People we consulted want a ‘home’ that is personally tailored to their needs.”*

Melbourne City Mission asserts that young people with disabilities – like other citizens – have the right to exercise housing choice – including the right to choose where they live and who they live with. Absence of housing choice and control perpetuates the discrimination and compounds the marginalisation that many people with disabilities already face.

¹² Youth Disability Advocacy Service (2013), *Housing and Support for Younger People with Disabilities Transitioning to Independent Living: Elements for Success in the Design and Implementation of DisabilityCare Australia, a National Disability Insurance Scheme*

¹³ Ibid.

An inappropriate housing option – case study

A major policy initiative of the past decade has been 'My Future My Choice' (MFMC). MFMC was the culmination of decades of lobbying to recognise the unmet needs of younger people in residential aged care and the disparity in accessing supports due to funding anomalies between State and Federal Governments. MFMC was the first program to be funded through both levels of government to assess and plan for the needs of younger people (under 50 years of age) residing in residential aged care. Melbourne City Mission was one of three agencies in the Victorian Department of Human Services' North and West Metropolitan region commissioned to undertake the assessment and planning phase of the 'My Future My Choice' initiative. In our assessment and planning, Melbourne City Mission consistently found:

- Participants were often the only person under 65 in their residential aged care setting.
- In interacting with residential aged care staff, planners found they appeared to have little understanding or knowledge of the complexity of care needs for young people in their care, particularly in relation to the specialist support needs for people with spinal cord injury, Acquired Brain Injury, Huntington's Disease, Multiple Sclerosis or intellectual disability.
- In some instances, aged care staff were hostile to young people with disabilities being in residential aged care – for example, our planners had interactions with staff who described young people as *"manipulative"* and *"sucking the system dry"*, and also noted instances where staff largely ignored the young people in their care.
- Participants with little or no verbal communication were deemed by staff to have dementia, although there was no medical evidence to support this diagnosis.
- Planners found that participants who had difficulty in communicating were often found in rooms by themselves with little opportunity for inclusion in activities or social interaction. Indeed, interaction with staff seemed to be limited to time spent on basic care needs. Some participants had not left the residential aged care facility for an outing since moving there, whilst others had not been able to access the external gardens due to a lack of equipment.
- There was little opportunity for young people to access community/mainstream services that could assist them to develop their 'voice', such as access to speech pathology, community advocacy or case management services.
- In some instances, planners found questionable practices in relation to personal care. Situations were disclosed where staff did not assist with showering, dressing, oral feeding or oral hygiene if alternative funded supports, such as Attendant Care workers, were employed through the 'Slow to Recover' program. It was noted that when no Attendant Care workers were available (e.g. public holidays, annual leave or sick leave) no personal care assistance was provided by aged care staff. Planners believed these instances may have exacerbated preventable conditions such as contractures, pressure sores, gingivitis and foot drop.
- The lack of basic equipment such as wheelchairs contributed to further isolation for young people and reduced any opportunity they may have had to access the community.
- Planners found a lack of appropriate day programs for people with acquired or degenerative disabilities.

Jimi's story – immediately below – shows that in 2015, there remains a critical shortage of age-appropriate community-based options for young people with disabilities and that, for those who continue to reside in the residential aged care system, provision of quality care continues to be an issue.

Jimi's story

Jimi, a Melbourne City Mission Disability Services client, is 57 years old and currently living in an aged care facility. Jimi had a stroke when he was 54.

For people with an ABI – for example, stroke survivors like Jimi – the initial two years post-injury represent a critical window. Jimi's family say a lack of clarity in the acute and sub-acute systems (including what they describe as constant changes to previously-agreed/ communicated courses of action in regard to rehabilitation) and, later, barriers to accessing other services/supports (for example, specialist ABI services in the community) adversely impacted Jimi's recovery and, hence, his ability to secure shared accommodation in the community with other young people with an ABI.

Jimi now has a Melbourne City Mission disability case manager visit him at least once a fortnight. The family say she is a great support: *"If it wasn't for her, Jimi wouldn't even get to take walks outside."* Notwithstanding this, Jimi continues to feel very isolated in residential aged care as the others living there are a generation older than him.

Jimi has also had to grapple with physical health problems that have emerged whilst in residential aged care. As noted earlier in this submission, young people with disabilities are highly susceptible to acquiring secondary conditions in residential aged care. Soon after Jimi was placed in his care facility, he contracted a Urinary Tract Infection and later required an operation. After three months of stable physical health, he experienced recurrent infections requiring a range of medical interventions. Jimi's family have noted a change in his mental health. Jimi's brother told Melbourne City Mission: *"I can't see Jimi now. About a year ago, Jimi's mental state worsened to the point where he told me to stop coming to see him. I can't go to see him now."*

If the family could recommend any changes to the system, it would be to assess the clients correctly, *"otherwise the client's life is ruined if the assessment proves to be wrong one. We were promised everything for Jimi and none of it was ever given."*

They would also recommend having specialist high-care facilities created for younger people, so they are receiving the right care in a place they can connect with people their age, with similar conditions.

Jimi's family have not been able to source funding for his high and complex needs, as well as for the aged care facility expenses. The family state that they *"feel so misled by this system"*.

"It costs a fortune to keep Jimi in the nursing home. They won't give him any help because Jimi has some savings, but it's not enough to keep him sustained forever. He will need financial assistance eventually."

Melbourne City Mission's response to Term of Reference (f)

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

As a consequence of deinstitutionalisation, people with disabilities are, in the main “*deciding on their own futures and expectations of life ... The changes include being able to decide what to eat, what to buy, what to wear, where to go, who to be friends with, education and training choices, to name a few.*”¹⁴

However, accessible, appropriate housing continues to be a critical challenge – a mismatch between supply and demand effectively removes choice for many young people with high-level support needs.

‘My Future My Choice’, which commenced in Victoria in 2006, was established to create new opportunities for young people living in residential aged care (or vulnerable to being admitted to aged care). Whilst it stimulated growth in new age-appropriate housing models in the community in its first five years, this growth has since stagnated.

Individuals and families tell Melbourne City Mission that they do not feel their expectations have been met. For example:

- There have been barriers to access for young people in residential aged care whose needs are stable (and therefore accorded lower priority).
- Those who **were** initially able to access community-based housing have, over time, provided evidence to Melbourne City Mission that resource constraints have impeded personal development, and health and wellbeing. (See Vicky’s story over the page.)

This underscores the critical need for initiatives to be adequately resourced, so that policy intent is fully translated in the funding and implementation phases.

¹⁴ Physical Disability Australia Ltd (2011), *A Home of My Own*

Vicky's story

Vicky is in her late thirties and sustained a brain injury more than a decade ago, as a result of an attempted suicide. She was in hospital for four months and then went to an ABI hospital unit for a few months. Vicky was then discharged back home.

Vicky qualified for the 'Slow to Recover Program', which gave her 35 hours a week of in-home care for eight years. When Vicky received a package to move into a 'My Future My Choice' residential unit, she lost all the 'Slow to Recover' funding assistance. She now has minimal personal care hours. Vicky's family told us: *"We have to rely on the staff availability to be able to take her anywhere. A lot of the time she doesn't go anywhere due to staff shortages."*

The withdrawal of care was a funding decision, rather than an outcome of a needs assessment. No assessment was completed to see whether Vicky still needed the in-home care, which she and her family still feel she very much needs, and the family state that there was no process by which they could complain or appeal the decision.

"[Without] this personal care funding, Vicky just wanders around the house. She can't go out unattended and there's nothing for her to do," say Vicky's parents.

"She was doing so well before they cut the funding for her in-home [care]. We saw a lot of progress. She has gone backwards as a result [of the loss of hours]. Her speech is worse than it was, her mobility has also worsened."

Having a supportive family, as helpful as it is to the client, can also place great pressure on families, according to Vicky's parents.

"As fantastic as it is to have a helpful and supportive family, it puts you further down the list for help because they then think you can do everything. This is where it's disappointing. We have worked so hard. Vicky has worked so hard. We don't want her to fall between the cracks."

"Vicky is thrilled to be living independently. We are trying to get her to the point where she can live without us to a certain degree. She needs to be around people her own age. When she's unhappy, we're unhappy and vice-versa. I became so fearful for her wellbeing at one point that I wanted to bring her back home, but we didn't. It wouldn't have been the best outcome for anybody."

"We just want her to be able to go out once a week, to a movie or something. Something she enjoys. Otherwise, her life is just working so hard at managing her disability – and that's it."

Melbourne City Mission's response to Term of Reference (h):

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

Melbourne City Mission welcomes the introduction of the National Disability Insurance Scheme, including the opportunity for eligible participants to access funds for home modifications to accommodate their needs. We also note that the scheme can assist participants to live independently with supports such as personal care to help with showering or dressing, or assistance with meal preparation and cleaning.

However:

- A young person's ability to live in the community depends largely on the community around them – in particular, their family. The NDIS makes reference to the informal supports that are 'part and parcel of family life'. However, we know from quantitative research that parents and siblings with caring responsibilities tend to have 'diminished life experiences and limited life prospects' across a wide range of indicators including physical health, mental health, income, housing and employment¹⁵. Familial circumstances are not always such that a young person can remain – or return – to the family home. Housing is consistently identified as an issue of concern for ageing parents of young people with disabilities who have high-level support needs.
- **Needs are complex.** People's needs vary based not only the person's physical support needs, but also – as mentioned above – their social and familial situation, as well as their aspirations and their own goals. "Appropriate accommodation" is therefore a difficult thing to measure globally and requires personalised responses. The NDIS schedule needs to account for this complexity.
- **The Federal Government has acknowledged that there is no guarantee that increase in funds through NDIS will lead to an increase in housing supply¹⁶.** As raised earlier in this submission, there are concerns that not many young people will be able to exit from residential aged care to more appropriate housing as a result of the NDIS. The NDIS supports will make a difference, insofar as young people in residential aged care who participate in the scheme will be able to access services that are not otherwise available in that setting. However, the fact remains that residential aged care is a highly inappropriate environment for a young person. The extra supports, whilst welcome, will merely serve as a bandaid for a bigger problem. The housing dimension is a major issue that is yet to be addressed.

¹⁵ Victorian Health Promotion Foundation (2012), *Disability and health inequalities in Australia research summary*, accessed at www.vichealth.vic.gov.au

¹⁶ <http://www.communityhousing.com.au/notes-from-the-housing-disability-and-ndis-forum/>

Conclusion

The notion that residential aged care is an inappropriate housing option for young people is uncontested by people with lived experience, and is reinforced by a rich body of research literature, including testimony to the 2005 Senate inquiry.

Young people are only entering residential aged care at the present time because there are no other options.

The NDIS is a landmark social policy reform that is based on principles of choice and control. Community expectations are high. Unless there is a strategy to address the issue of housing supply, people's pathways to inclusion and participation will be frustrated.