



Youth Affairs
Council Victoria

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

5 February 2015

To the Committee Secretary

Re: Senate inquiry into the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia

I am writing to you as the Manager of the Youth Disability Advocacy Service (YDAS) in response to your request for submissions to the Senate inquiry into the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia.

YDAS is a Victorian advocacy service that works alongside young people with disabilities between the ages of 12 and 25 to raise awareness of their rights and to support them to achieve what they want. YDAS is a service of the Youth Affairs Council of Victoria (YACVic). We are funded by the Office for Disability.

YDAS provides one-on-one support through our individual advocacy service and we also work on broader policy issues affecting young people with disabilities through our systemic advocacy. This broader work is directed by the YDAS steering committee whose membership is made up of young people with a range of disabilities from across Victoria.

We appreciate the opportunity to make this submission to the Community Affairs References Committee.

Young people with disabilities who need support to live independently face many challenges. These relate to their level of confidence in their ability to live independently, the confronting concerns held by family, friends and carers about

their safety and survival, and the difficulty involved in securing flexible supports and accessible and affordable housing.

In 2013, YDAS undertook a research project that investigated how to best address the housing and support needs of young people with disabilities.

This research involved a multi-pronged approach to data collection. It included a systemic review of the literature, an online survey with a separate questionnaire for people with disabilities and family members, qualitative research involving face to face interviews with people with disabilities, their families and advocates, and interviews with peak bodies and specialist agencies.

The literature review was clear in identifying that ordinary housing, dispersed within the community, where there is access to individualised supports, consistently outperforms clustered and institutional settings in measures of social inclusion, interpersonal relationships and in material, emotional and physical well-being. The review demonstrated that widely held beliefs - that individualised approaches are too expensive or difficult to implement - are not validated by the evidence. The research showed that providing tailored, individualised supports in the person's home is less expensive over time, with direct financial savings to the broader health and public services system and improving the individual's ability to take up paid employment. It also challenged the idea that people with higher support needs can only be housed in group or congregate care settings such as group homes, residential care facilities and nursing homes.

The research found that while there is no one 'model' of service which should be considered as guaranteeing success, there were key benchmarks or principles that effective housing and support for people with disabilities can be measured up against:

1. Accessible Quality housing: housing stock must be of a good quality, **physically accessible** to the individual and their social network.
2. Affordable housing, the cost of housing must **allow for sufficient disposable income** to afford more than just the necessities of life, but a good life.
3. Homeliness: the individual's home should remain **a private space, suited to their preferences and tastes**, and free of the demands of formal service regulations that compromise the individual's freedom in their home.
4. Tenancy Rights: people with a disability must be **afforded typical tenancy rights and responsibilities**. They should have the right to give notice and move on and to appeal to tenancy decisions.
5. Choice of where you live and with whom you live with: the individual must make the decisions about their living and support arrangements. All people

should choose who they live with and should **not be forced to live with others for the sake of cost-efficiency or service provider convenience**.

6. Safeguards: the individual should have personal safeguards for their well-being. This means that there are **suitable emergency backup procedures** in place and that the individual is not totally reliant on a single service provider who may fail to deliver critical supports.
7. Investment in assistive technology: this can **enhance independence and safety** and reduce long-term costs
8. Separation of tenancy from service provision: This means that the person can **change service providers without losing their tenancy** and they can also move house and retain their service provider.
9. Opportunity for friendships and sexual relationships: Housing should **maximise opportunities for the individual to build and maintain strong relationships** with a partner, family, friends and other relationships as they choose. This can be facilitated with a homely environment where **a person can have other people close to them, stay over or move in with them**.
10. Community belonging: housing and supports provided should concentrate carefully on ensuring **the individual has connection to their local community** in ways that they choose to. This means that they have sufficient supports to get a life, an education, and a job
11. Choice of support staff: People with disabilities benefit from having choice over who delivers their support. Situations where the individual and their family have had the **capacity to recruit, train and dismiss** their own staff reflected a great deal of satisfaction with support arrangements.
12. Phased steps towards living independently: The chance to experiment with independent living and to **have trials** was an important step in the process. For example, opportunities to live in an ‘independence training flat’ before moving out.
13. Access to information and peer support: people benefit from **learning about a range of housing and support arrangements** and experiences and learning from the successes as well as the challenges of people in similar circumstances.

It is clear that residential care arrangements in Australia, and especially nursing homes, fail to reach most of these benchmarks. While residential care in Australia may be accessible, affordable and include some safeguards, it is unlikely to be homely, tenancy rights are limited, you have little choice about where you live and who you live with, access to assistive technology is limited, tenancy and service

provision are intertwined, you are often removed from your chosen community and family networks, you have no choice over your support staff, your independence is reduced and you have little access to information and support.

Current approaches to housing and support for people with disabilities, where many are forced to live in nursing homes or in other forms of segregated residential care is a breach of the United Nation Convention on the Rights of Persons with Disabilities to which Australia is signatory. It is a serious concern that Australia is failing to meet its obligations, specifically to Article 19 “Living independently and being included in the community” which asserts the equal right of all persons with disabilities to live in the community, with choices equal to others, and (signatories) shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

We concur with the Summer Foundation in their submission to your Committee, that Australia desperately needs a long term strategy to create more housing that is both accessible and affordable. Rather than continuing to build segregated specialist housing, addressing the housing needs of people with disability needs to be incorporated into mainstream housing strategy.

With the current rollout of the NDIS and with the entitlement to reasonable and necessary support enshrined in legislation, there is an urgent need to redefine how our country responds to the housing needs of people with disabilities. As the availability of support increases through the provision of individualised support packages, there will be a significant increase in demand for accessible and affordable housing in the community.

In our research we found examples of exemplary practice that are delivering on the kind of outcomes that people with disabilities and families desire, enough to show that it can be done well. We must expand these approaches across the country. We have learnt that people with disabilities and their families and supporters are an

untapped creative resource. The Australian Government needs to support co-design and co-production that will bring this experience and knowledge to the table.

Consultations across different jurisdictions highlight a common demand for trustworthy information. Many consumers of disability services complained about the lack of good information and support from their current service provider and are increasingly wary of the competing and conflicting interests between provider and consumer. They would like to see peer support structures, independent advocacy and information resources that encourage consumer empowerment and informed decision-making. Furthermore, there is clearly a need for a choice of dwelling types in a variety of locations that are both accessible and affordable.

While the provision of housing rests with housing authorities and urban planning arms of government, we believe that they need to provide a greater commitment to accessibility and affordability. Furthermore, greater investment is needed by all levels of government to increase accessibility and affordability in both the social housing and private housing markets.

We hope that we have highlighted some key issues for consideration with respect to the adequacy of residential care for people with disabilities in Australia. We believe there is a compelling case for increased investment in accessible and affordable housing in the community. The provision of disability support in the community as opposed to segregated settings supports a mix of paid formal supports with the informal and natural supports that are available within our communities. Investment in housing and support in the community has a potential positive benefit not only to the quality of life for people with disabilities but also to the Australian government's financial bottom line. We believe that the benchmarks that we have put forward should inform all future policy and practice in the area of housing and support for people with disabilities.

We would be happy to discuss this further, so please don't hesitate to contact me on (03) 9267 3755 or by email YDASmanager@yacvic.org.au

Yours Sincerely,

Dr George Taleporos

YDAS Manager