



Youth Affairs
Council Victoria

Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100
Parliament House
Canberra ACT 2600
To the Committee Secretary

22 February 2016

Re: Accommodation for people with disabilities and the NDIS

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 core agency of the Youth Affairs Council of Victoria (YACVic). We are funded by the State Government of Victoria.

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.

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.

We appreciate the opportunity to make this submission to the Joint Standing Committee on the National Disability Insurance Scheme. In our submission, we will:

1. Outline the findings from our research about key benchmarks/principles for effective disability housing and support

2. provide real-life experiences of young people with disabilities living in inappropriate accommodation
3. highlight Australia's international obligations for Housing under the United Nation's Convention on the Rights of Persons with Disabilities

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 and most community residential units (group homes), fail to reach most of these benchmarks. While they may be accessible, affordable and include some

safeguards, they are 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.

Real-life case studies from YDAS clients

Through our individual advocacy work, we have seen what happens in people's lives when the above principles are not included in their housing arrangements.

Kelly, a 22-year-old woman living in a Community Residential Unit who has physical disabilities and requires full assistance with toileting, menstrual care and showering, made multiple complaints to staff about the lack of female support workers. It is unacceptable to her, and an abuse of her right to bodily autonomy, to be forced to have her personal care needs attended to by male staff. This has resulted in her foregoing showers and delaying bowel movements, leading to multiple and very serious health problems. Kelly was very anxious about staff finding out that she is accessing advocacy services for fear of retaliation and further neglect but could not attend meetings outside the Unit to discuss her case because she needed attendant care to leave the house which is not provided for her. (YDAS client, February 2015)

Kelly's experience highlights the importance of choice of support staff and the need to separate tenancy from service provision. The service provider in this case is also the landlord and Kelly has little say when it comes to who provides her support. Staff recruitment is a decision made by the service provider and Kelly has no right to choose who supports her within the home. Kelly wants and deserves the right to choose who touches her body. She also has no ability to change service providers because the service provider owns the home.

Jack, a 17-year-old male living in a Community Residential Unit, who has autism and uses non-verbal communication, was one-of-two people allegedly sexually assaulted by a new co-resident with a well-known history of sex offending, not long after he moved in to the Unit. The families of the existing residents made multiple complaints to the service provider and to the DHHS about the inappropriate placement before the alleged assault took place, but were dismissed as over-zealous and intolerant. Jack's family were not informed by the service provider about the alleged assault but from the family of the other victim, who needed medical attention for his injuries. The staff member working at the time of the alleged assault did not take steps to prevent the attacks, hiding himself in the locked staff area. He was not dismissed by the service provider despite admitting negligence. Jack's family

are lobbying to have him moved into more suitable housing but must negotiate these new arrangements with the same DHHS staff who have threatened to apply for guardianship if they persist with their complaints. (YDAS client, April 2015)

Jack's experience reflects the lack of housing options for young people with disabilities who are far too often inappropriately housed in Community Residential Units with much older people and have no say with respect to who they live with. Jack's experience also demonstrates the abuse and neglect that can take place when we house people with behaviours of concern in segregated group settings. The NDIS must provide better options.

Kelly and Jack's experiences are typical of the many young people for whom the current housing and support system is failing. To illustrate how common negative experiences of congregate care arrangements are

- A 13-year-old boy who was placed in an adult group home and assaulted by residents.
- A 26-year-old man who threatens suicide weekly as a response to his desperation to leave an unsuitable supported accommodation service. No other placements are available.
- A 19-year-old man whose group home staff are limiting visits home to his mother despite his wishes to see her more often, not less.
- A 15-year-old boy who is living in out-of-home care with no funded disability supports with staff who have no disability-specific training. He spends weekends on the streets involved in criminal activity.
- A 19-year-old woman who was placed in a group home with three elderly men.

Their experiences inform our policy work and evidence the need to develop a housing strategy that meets the 13 benchmarks discussed earlier in our submission.

Australia's Human Rights Obligations

It is also important that the Joint Standing Committee consider Australia's obligations under the United Nation's Convention on the Rights of Persons with Disabilities (UNCRPD) to which Australia is signatory. Current approaches to housing and support for people with disabilities, where many are forced to live in segregated and often abusive housing arrangements is a breach of the UNCRPD.

It is a serious concern that Australia is failing to meet its obligations.

Firstly, with respect 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.

Secondly, Article 16 “Freedom from exploitation, violence and abuse” says that states shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects. In accordance with this, we call on government to cease institutional style accommodation where people with disabilities are congregated together and where abuse violence and exploitation are rife.

Conclusion

Australia desperately needs a long term strategy to create more housing that meets the benchmarks that we described earlier in our submission. For this to happen, we need to stop building segregated housing, and instead we must incorporate the housing needs of people with disability into a 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.

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 housing 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