



DANA Disability Advocacy
Network Australia

The inadequacy of existing residential care arrangements for young Australians with severe disabilities

Submission to the Senate Community Affairs References Committee

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About Disability Advocacy Network Australia (DANA) Ltd

Disability Advocacy Network Australia (DANA) is the national peak body for almost 70 disability advocacy organisations across Australia. Our goal is to advance the rights and interests of people with disability by supporting our members in their targeted advocacy as well as engaging in systemic advocacy on a national level to further these objectives. DANA works to a vision of a nation that includes and values persons with disabilities and respects human rights for all.

Independent advocacy agencies address the advocacy needs of those people with disabilities who are more likely to be vulnerable to abuse, neglect and/or breaches of their fundamental human rights. They do this through a variety of delivery models that include systemic advocacy, legal advocacy, individual advocacy support by paid advocates, citizen advocacy using volunteer advocates, self advocacy development and family advocacy development and support.

Introduction

DANA welcomes this inquiry and the opportunity to make a submission on this important issue for Australians with severe physical, mental or intellectual disabilities, for their families and friends and for disability advocates. Many people with disabilities are currently compelled to live in institutional settings, including residential aged care, which restrict individual freedom and decision making, and segregate and isolate people from the wider community, in environments that often foster violence, abuse and neglect. This submission will address several of the Terms of Reference.



d. The appropriateness of the aged care system

The aged care system is highly inappropriate for the accommodation and support of young people with serious and/or permanent mental or physical disabilities and it is not compliant with Australia's obligations under international human rights law.

The UN Convention on the Rights of Persons with Disabilities

Australia ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2008, agreeing to be bound by its terms within the international community. Articles of the CRPD apply rights recognised in general human rights treaties to the context faced by people with disabilities, elaborating on how human rights obligations can be implemented in relation to disability. They provide for special measures or supports to enable all people with disabilities to access and exercise those rights. In the context of accommodation, Article 19 provides a clear articulation of those rights that Australia should immediately seek to progressively realise.¹

In Article 19 the CRPD articulates the rights of people with disability "to live in the community, with choices equal to others, and... 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...; [with] access to a range of in-home, residential and other community support services..."²

These rights are clearly violated when young people with disabilities are placed in residential aged care facilities in order to receive the high level of support needed, as they are forced to live isolated from people their own age and cut off from the wider community.

In October 2013, the UN Committee provided specific guidance to Australia on implementing these obligations:

*"The Committee encourages the State party to develop and implement a national framework for the closure of residential institutions and allocate the resources necessary for support services that would enable persons with disabilities to live in their communities. The Committee recommends that the state party takes immediate action to make sure that persons with disabilities are given a free choice of where they want to live and with whom and be able to receive the necessary support regardless of the place of residence. The State party should therefore conduct a mapping of the various forms of living accommodation based on the needs of various kinds of persons with disabilities."*³

National Disability Strategy

In 2011, the COAG endorsed the National Disability Strategy 2010-2020 (the Strategy). It provides a framework for Australia to address its CRPD obligations, particularly in establishing a coordination mechanism (as recommended in Article 33) to facilitate implementation in different sectors and at different levels. The vision and principles of the Strategy rightly reflect the aspirations of the CRPD

¹ Phillip French 2010, *Accommodating Human Rights: A human rights perspective on housing, and housing and support, for persons with disability*, People with Disability Australia.

² United Nations *Convention on the Rights of Persons with Disabilities*, Article 19.

³ Concluding observations on Australia, adopted by the Committee on the Rights of Persons with Disabilities at its tenth session 4/10/2013. CRPD/C/AUS/CO/1. [42].



and the challenge now facing Australian governments is planning and taking effective action to make this a reality. A number of the Strategy's policy directions and areas for future action are particularly relevant.

Suitable accommodation features under Outcome 1 - inclusive and accessible communities. Policy Direction 3 is the "improved provision of accessible and well-designed housing with choice for people with disability about where they live."⁴ Universal design principles are also highlighted.⁵ Housing is also featured under Outcome 3 - economic security. Policy Direction 3 is to "Improve access to housing options that are affordable and provide security of tenure." Under Outcome 4, personal and community support, the continued development of innovative and flexible support models for people with high and complex needs is identified as an "area for future action". Supported accommodation is listed as one these models, despite often being used to refer to practices that do not allow free choice and would not comply with Article 19 of the CRPD.⁶

These aspirations will only be achieved through long-term investments of funding, innovative policymaking and coordinated governance. To achieve the Strategy vision of "an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens" there must be broader and deeper mechanisms allowing people with disabilities to have direct input into policymaking. Ongoing engagement and consultation with people with disabilities has been identified as vital, and opportunities to have a say and be listened to, must be made more accessible and meaningful. It is hoped the voices of young people with severe disabilities who live, or have lived, in an aged care facility will be heard by the Committee during this Senate Inquiry.

Listen to the voice of the people, listen to the lived experience.

...listen to people with disabilities and their families and advocates first and foremost.⁷

Aged care does not stimulate or offer recreation activities for the young. Music, games, entertainment, meals, meal times, wake and retire to bed times, are all structured around an aged person... Current jurisdictions do not consult with or respond to the organizations supporting young people with disabilities. Having people on a Register of Need is ticking the boxes in administrations. Politicians need to integrate and listen to the issues and really hear ... Until such time ... there will be no real understanding of the issues and lack of resources available to allow people a quality of life.⁸

e. Alternative systems of care

Outside of the aged care system there are accommodation models that do give effect to self-determination, inclusion and equality for the individual. Yet many people with severe disabilities

⁴ Council of Australian Governments (2011) *National Disability Strategy 2010–2020* (Commonwealth of Australia, 2011) 16.

⁵ *Ibid*, 30.

⁶ *Ibid*, 52.

⁷ Quotes from 2014 survey responses: Outcome 4: Personal and Community Support and Outcome 6: Health and Wellbeing.

⁸ Independent Advocacy Townsville (2015) *Submission to the Senate Standing Committees on Community Affairs*, 3-4.



cannot access such options and have continued to live in housing and service arrangements that are not consistent with human rights:

“...people with disability have very few housing options and very limited housing careers. This is due to the cost of support when living independently, and the lack of affordable and accessible private housing for most people with disability.”⁹

For instance, advocates have provided these case examples of housing and service cost pressures placing severe limits on the life and accommodation choices of individuals with disability:

A person who is currently in a social housing property is subject to ongoing harassment and abuse by neighbours. The person has been waiting for a transfer for at least six months and has been advised that it will still be a long wait - even the best case scenario would be a further six months. Whilst remaining in this property the person has developed serious health problems related to the harassment and abuse and is now taking psychotropic medications to cope.

Person must rely on services to assist to go to bed and to get up, and is unable to decide to go to bed at a later time or have a sleep in as they need to fit in with the support arrangements, and the costs associated with it.

A person with disability who is non-verbal may not want to go into respite all week. A family believes that the person needs to go into respite all week. There is a conflict between the person's right to be heard and the family. If the person with disability does not have an independent advocate, there will be no independent voice to represent the interest of the person with disability.

A lady decided that she wanted to go to bed an hour later on a Sunday evening and this ended up being an unaffordable cost to her of about \$70 p/h.¹⁰

Client B has been living in aged care and in public hospitals for the past 3 years. Client B is from (redacted) where he has a large family and friends and has an aged mother living in an aged care facility in (redacted), who he never has the opportunity to visit. Client B has always maintained and articulated his wish to live where he can have family support. This person is currently on the Register of Need and a Department spokesperson has advised Independent Advocacy Townsville on two separate occasions “Client B has a roof over his head, so his needs are being met, though inappropriate”¹¹.

Accessible and affordable community based accommodation is vital to creating the inclusive future envisaged by the CRPD and the National Disability Strategy.

⁹ Bruce Bonyhady, “Living independently: A guide to the NDIS and housing,” HousingWORKS, December 2013.

¹⁰ Case examples from 2014 surveys: Outcome 2: Rights Protection, Justice and Legislation; Outcome 3: Economic Security; and Outcome 4: Personal and Community Support.

¹¹ Independent Advocacy Townsville (2015) *Submission to the Senate Standing Committees on Community Affairs*, 4.



Choices limited and constrained

Although there have been positive developments in the use of accessible and universal design, including Livable Housing guidelines and certification, DANA's survey of disability advocates in 2014 found that the majority had observed little or no significant improvement in the provision of accessible well-designed housing. People with disabilities experience higher rates of discrimination and lower rates of employment, and often find themselves practically excluded from owning or renting a home, vulnerable to homelessness, and reliant on public or social housing, which may be unavailable or inadequate. Difficulties in finding secure, stable accommodation may be compounded by the shortage of accessible housing, culturally appropriate housing or housing located in easy proximity to public transport, amenities and services. Modifying accommodation to be accessible and responsive to individual needs is often problematic or costly, due to the limited use of universal housing design principles.

In our 2014 engagement on economic security outcomes all advocates surveyed unanimously agreed that access to affordable secure housing options had shown little or no significant improvement. The current housing affordability crisis disproportionately affects people with disabilities, and demand is simply not being met by current housing stocks:

Accessible and appropriate housing is horribly under-resourced. People with disabilities are waiting around 12 months on the "priority" housing list, when the typical wait expected is 3 months. They are waiting in totally inappropriate and sometimes dangerous conditions for extended periods of time. This is because there is not enough accessible housing, and also because people with disabilities do not have access to adequate supports to move from supported accommodation environments.

Even if housing were available at a reasonable cost (which it is not), many people are unable to access the funding they need that would support them to live independently in a place of their own. This results in many people with disability residing with their ageing parents who struggle with their care

In our state there is a lack of Public housing full stop. A person with a disability on the priority housing list may have to wait 2 years for housing.¹²

Furthermore, the housing choices of people with disability are often constrained by the tying of specialist disability supports to accommodation facilities.¹³ Many young people with severe, physical, mental or intellectual disabilities (particularly those with high or complex support needs), are currently compelled to live in residential care, including nursing homes, in order to access the support they need. This model is contrary to the human rights obligations of the CRPD, as it restricts a person's rights and opportunities, segregates and isolates from the community, and often limits access to independent and person-centred advocacy and support.¹⁴

In a 2014 DANA survey, an advocacy agency observed that:

¹² Quotes from 2014 survey on Strategy progress under Outcome 3: Economic Security.

¹³ People with Disability Australia 2014, *Submission to Legislative Council Select Committee Inquiry into Social, Public and Affordable Housing* p. 5.

¹⁴ *Ibid* p. 6.



People are still being placed in accommodation services rather than living in a home that reflects their needs, their wants, their personality, their preference.... Systems and services for this cohort are most responsive to the needs of paid workers, services and government than the people themselves. Improvements in regard to design principles, accessible public transport and communication and information systems are impotent when a person spends the majority of their life in a group home, boarding house, or other residential facility.”¹⁵

In the context of the current Royal Commission into institutional responses to child sexual abuse, it is well established that institutional living accelerates the occurrence of abuse, neglect and exploitation of people with disabilities.¹⁶ Group homes continue to impinge upon human rights by creating violent, unstable environments that unnecessarily restrict freedom yet offer little protection from abuse, intimidation or harassment.¹⁷ The Four Corners report in November 2014 drew attention to the occurrence of disability abuse, including cases of sexual assault, exploitation and rape in residential services and institutional settings.

Despite clear evidence of the detrimental aspects of congregate living arrangements, some governments continue to license and fund institutions, and some are being redeveloped into ‘contemporary’ institutions that continue to congregate people with disability and segregate them from the community, including group homes and cluster villages.¹⁸ Australia must heed the recent recommendation of the United Nations Committee on the CRPD to ensure future initiatives in Australia do not simply “replicate institutional living arrangements” and compel people with disabilities to live in residential institutions to receive the necessary supports.¹⁹

In our 2014 engagement with disability advocates, some survey respondents acknowledged increased understanding of person-centred approaches among disability service providers, yet noted that it remains highly inconsistent and dependent on individual workers. They also expressed apprehension that positive changes would not reach all intended beneficiaries, without additional measures for supporting access and for building capacity for self-directing, planning and self-advocacy among participants. Some are also wary of signs indicating:

reversion of thought within government and service sector that seeks to restrict and limit opportunities for people with a disability and their families by a risk management approach to change.

There is also concern about service providers changing only superficially, using language to mask failures to truly embrace self-direction or self-determination:

¹⁵ Quote from 2014 survey on Strategy progress under: Outcome 1: Inclusive and Accessible Communities.

¹⁶ People with Disability Australia 2014, *Submission to Legislative Council Select Committee Inquiry into Social, Public and Affordable Housing* p. 5.

¹⁷ Price-Kelly S and Attard M 2010, *Accommodating Violence: The experience of domestic violence and people with disability living in licensed boarding houses*, People with Disability Australia. National Disability Strategy engagement – Survey response – Rights Protection, Justice and Legislation.

¹⁸ Taleporos G, Craig D, Brown M, McNamara C and Forbes S 2013, *Housing and Support for Younger People with Disabilities Transitioning to Independent Living: Elements for Success in the Design and Implementation of National Disability Insurance Scheme*, Melbourne: Youth Disability Advocacy Service and Youth Affairs Victoria Inc. p. 27-28. People with Disability Australia 2014, *Submission to Legislative Council Select Committee Inquiry into Social, Public and Affordable Housing* p. 10.

¹⁹ Concluding observations on Australia, adopted by the Committee at its tenth session 4/10/2013. CRPD/C/AUS/CO/1. [41].



The high-jacking of such approaches as "person-centred" supports and "choice and control" is usurped by the service sector and regurgitated as a rebranded program of "choices". Yes the language is more broadly used, but the practices employed are far from valid.

Person centred planning is a buzz word that usually means we can meet your personal needs and wants but only within the confines of our congregated or segregated service - so maybe people get to choose what they wear from their cupboard of donated/second hand clothing, or maybe they get to choose to go dancing but only at the day option not the local pub.

Service providers have run community engagement programs without offering choice and bussed people with disabilities to a local club as an engagement, instead of asking the person with disability about their particular interests and seeing how that person could be welcomed into the local mainstream art society, or train watchers, or birding or golf, swim club or footy.²⁰

From compulsion to choice and control

A safe, appropriately designed environment which provides privacy, personal space, accessible facilities, and adaptability is central to the wellbeing of people with disabilities.²¹ Living in the community is bound up with a range of other positive outcomes, such as increased social and economic participation, which leads to greater quality of life.²² Housing policies should be coordinated with other relevant areas in a national whole-of-government approach.

Australian governments must refrain from supporting (for instance, through grants of land or funding) the promotion and redevelopment of institutional models that diminish the choices of people with disability to select their own supports *and* their own housing. There is an inherent risk of compromising choices when funding housing through agreements between social and community housing organisations and disability service providers.²³ Government policies should also avoid endorsing strongly one specific type of housing or design and rather embrace flexible responsive design that can maximise the independence of residents and be adapted with ease according to needs and diverse preferences.²⁴

As the United Nations Committee recommends, the Australian government should "conduct a mapping of the various forms of living accommodation based on the needs of various kinds of persons with disabilities".²⁵ Built environment professionals, designers, property professionals etc. should work together, and directly engage with people with disabilities to develop innovative and varied housing options.²⁶ A wide variety of options is needed to adequately cater for the wide range of access, support, family, cultural, locational and personal needs of people with disabilities.

²⁰ Quotes from 2014 survey on Strategy progress under Outcome 4: Personal and Community Support.

²¹ Urbis 2013, *Disability Care and Property*, 5.

²² People with Disability Australia 2014, *Submission to Legislative Council Select Committee Inquiry into Social, Public and Affordable Housing* p. 5.

²³ Ibid p. 11.

²⁴ Jackson M A, quoted in Urbis 2013, *Disability Care and Property*, p. 5.

²⁵ Concluding observations on Australia, adopted by the Committee at its tenth session 4/10/2013. CRPD/C/AUS/CO/1. [42].

²⁶ Jackson M A, quoted in Urbis 2013, *Disability Care and Property*, p. 5.



f. Considerations of de-institutionalisation

Moving out of an institution requires careful planning to ensure the necessary supports are in place and a considered assessment and minimization of any risks. For instance, people with disabilities or mental illness leaving institutions to live in the community have sometimes been placed in inappropriate accommodation, such as licensed boarding houses. A 2013 study found that this form of accommodation does not contribute positively to residents' quality of life or serve to enact the human rights principles articulated in current policy and legislation.²⁷ Research by Price-Kelly and Attard revealed that people, and especially women, with disabilities residing in licensed boarding houses are highly vulnerable to domestic violence.²⁸

h. The impact of the introduction of the NDIS

The introduction of the National Disability Insurance Scheme is expected to have a positive impact on the ability of young people in aged care facilities to find more appropriate accommodation. However, major challenges and uncertainties remain around how the demand for affordable, accessible housing will be met.²⁹

The introduction of the National Disability Insurance Scheme (NDIS) is reforming the provision of funding for disability services and supports, with the aim of enabling individuals with disabilities to exercise "choice and control" over their lives. With access to supports which can be delivered flexibly in the community, NDIS participants will place greater demands on the housing system to provide accessible, affordable options that cater to their needs and preferences, and maximise their ability to live independently. This is a vital moment for Federal and State and Territory housing policies and the Australian housing sector to engage with and integrate these principles and find ways to meet this demand. Only through substantial reform and investment will people with disabilities obtain access to sufficient affordable options in the range of accessible, flexible community-based housing, to truly exercise the fundamental right to choose where and with whom to live.

The scheme is intended to allow participants to exercise control and choice over their disability supports. It is hoped the NDIS will act as a catalyst for transformative growth in disability housing. However, the Agency will not solve the lack of affordable and accessible private housing for people with disability.³⁰ Indeed, the scheme's launch will increase the pressure on the housing system to accommodate the needs of people with disabilities seeking better housing options.³¹ Over half of the intended participants are expected to be on a very low incomes and have limited means to

²⁷ Gabrielle Drake (2013) 'The Transinstitutionalisation of People Living in Licensed Boarding Houses in Sydney' *Australian Social Work*

²⁸ Sonya Price-Kelly and Maria Attard (2010) *Accommodating Violence: The experience of domestic violence and people with disability living in licensed boarding houses*, People with Disability Australia.

²⁹ In June 2014, the Agency expected to soon circulate a discussion paper for consultation on these issues, but this has not yet occurred.

³⁰ Bruce Bonyhady, "Living independently: A guide to the NDIS and housing," *HousingWORKS*, December 2013, 16-17, 16.

³¹ People with Disability Australia (2014) *Submission to Legislative Council Select Committee Inquiry into Social, Public and Affordable Housing* 3.



meet all their housing needs through the private rental or ownership market.³² The legislation does not allow for accommodation to be part of a person's support package.³³ Funding will only be provided for reasonable and necessary supports where individuals not already entitled to service from existing general services.³⁴

Many NDIS Participants are expected to finally realise their right to live in the community rather than in residences that are tied to their support provision. Such reasonable expectations in turn increase expectations of housing systems, especially regarding demand for flexible community-based housing and an upsurge in renovations to existing housing stocks to improve accessibility.³⁵ To truly commit to the principles enacted for the National Disability Insurance Scheme, Australian governments must address the shortage of affordable and accessible accommodation for people with disability.

³² Bruce Bonyhady, "Living independently: A guide to the NDIS and housing," HousingWORKS, December 2013, 16-17, 16.

³³ Except for some potential supplementary funding (undefined) where disability leads to higher costs, NDIS, Mainstream interface: Housing and independent living Fact Sheet, 16 January 2014.

³⁴ s34, *National Disability Insurance Scheme Act 2013* (Commonwealth)

³⁵ Urbis (2013) *DisabilityCare and Property*, 4.