

A voice of our own

# Realising our right to live independently in the community

Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability in response to the *Group Homes Issues Paper* (28 Nov 2019)

## About PWDA

**People with Disability Australia** (PWDA) is a leading disability rights, advocacy and representative organisation of and for all people with disability. We are the only national, cross-disability organisation – we represent the interests of people with all kinds of disability. We are a non-profit, non-government organisation.

PWDA's primary membership is made up of people with disability and organisations primarily constituted by people with disability. PWDA also has a large associate membership of other individuals and organisations committed to the disability rights movement.

We have a vision of a socially just, accessible and inclusive community, in which the human rights, belonging, contribution, potential and diversity of all people with disability are recognised, respected and celebrated with pride. PWDA was founded in 1981, the International Year of Disabled Persons, to provide people with disability with a voice of our own.

PWDA is a NSW and national peak organisation and founding member of Disabled People's Organisations Australia (DPO Australia) along with Women with Disabilities Australia, First Peoples Disability Network Australia, and National Ethnic Disability Alliance. Disabled Peoples Organisations (DPOs) are organisations that are led by, and constituted of, people with disability.

The key purpose of DPO Australia is to promote, protect and advance the human rights and freedoms of people with disability in Australia by working collaboratively on areas of shared interests, purposes, strategic priorities and opportunities.

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## 1. Introduction

PWDA welcomes the opportunity to respond to the *Group Homes Issues Paper*, published by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Commission) on 28 November 2019.

Many people with disability in Australia face significant barriers in their right to live independently and be included in the community, and are denied the right to choose freely where they live, and with whom they live. The slow progress of successive governments at the state and Commonwealth levels to develop and roll out accessible social and private housing options, and appropriate and portable support services, are key barriers to enabling people with disability to live in the community, rather than in segregated congregate settings. These include group homes as well as other forms of congregate living, such as boarding houses, assisted boarding houses, rooming houses and hostels.

Research and numerous inquiries have shown that people with disability are more likely to be exposed to violence, abuse and neglect from disability support providers, people who are paid to provide support, and other residents, particularly in congregate residential settings. This is reflected in data on reportable incidents across all states (except WA) lodged with the National Disability Insurance Scheme (NDIS) Quality and Safeguards Commission for the three-month period from 1 July 2019 to 30 September 2019. Of the 8,595 serious incidents reported within the NDIS:

- 6,694 were reports of unauthorised restrictive practices
- 1,236 were reports of alleged abuse and neglect (including physical violence, sexual abuse/violence, verbal abuse and financial abuse)
- 437 were reports of known serious injury
- 228 were reports of deaths.<sup>1</sup>

First-hand accounts of the violence and abuse to which people with disability have been exposed in congregate residential settings by others have been well documented over the decades. Individual stories have been disclosed to advocates, and recounted in complaints and appeals; and intermittent media interest has provided opportunities to expose systemic abuse. As noted in the Commission's Issues Paper, most of the large residential institutions that were the highest profile sites of violence, abuse, neglect and exploitation of people with disability have been closed down. However, group homes remain part of the system, currently housing approximately 17,000 people around Australia.

PWDA advocates and program partners report that the violence, abuse and neglect that occurs within group homes includes, but is not limited to:

<sup>&</sup>lt;sup>1</sup> 2019-2020 Budget Estimates Hearings, Hansard. As reported by Guardian Australia – <a href="https://www.theguardian.com/australia-news/2020/jan/31/ndis-watchdog-is-fielding-nearly-100-allegations-of-abuse-or-neglect-a-week">https://www.theguardian.com/australia-news/2020/jan/31/ndis-watchdog-is-fielding-nearly-100-allegations-of-abuse-or-neglect-a-week</a>



- physical abuse by staff and other residents, including biting resulting in cuts, bruising, broken bones
- neglect
- overmedication/mismanagement of medication including a lack of ongoing professional medical review
- emotional and psychological abuse including coercion, social isolation, withdrawal of food/social outings
- restrictive practices (the use of physical, chemical, mechanical, and social restraint, detention, seclusion and exclusion); and
- financial abuse.

Our advocates report incidents of violence, abuse, neglect and exploitation to the relevant Government oversight bodes. However, it is our experience that investigations can take considerable time. So while investigations are taking place, advocates also work hard to find safer and more suitable housing, most often in community or social housing. However, finding suitable alternative housing can itself being challenging as social housing stock is limited, waiting lists are long, and much social housing is not fully accessible.

PWDA's policy positions regarding group homes have been informed by our advocacy work with people with disability who live/have lived in segregated congregate settings. In our advocacy work we continue to see old systems and practices that can drive and/or expose residents to abuse and violence. Unfortunately, these systems and practices are being replicated in the NDIS, which continues to promote and promulgate congregate living in group homes as part of the Scheme, despite well-known and well-documented risks and experiences for people with disability of violence, abuse, neglect and exploitation in these settings.

In this submission PWDA argues that:

- group homes must be phased out
- people with disability are entitled to have access to suitable housing options in the community, with appropriate supports
- a clear, robust and properly resourced plan to transition away from group homes needs to be developed and implemented as a matter of urgency.



## 2. List of recommendations

**Recommendation 1** – That a transition plan be developed to achieve the following outcomes:

- 1. All congregate housing, including group homes, be phased out urgently and according to a clear target deadline.
- 2. No new people with disability to enter congregate housing, including group homes.
- 3. Proper resourcing is provided to improve contemporary, accessible and affordable housing options.
- 4. All people with disability living in congregate housing be relocated to contemporary, accessible and affordable housing options as a matter of urgency.
- 5. People with disability are provided with the essential supports and services needed to transition from congregate housing to living independently in the community.

**Recommendation 2** – That a transition plan away from group homes is developed as a matter of urgency, and it is led, implemented and monitored by people with disability.

**Recommendation 3** – That governments strengthen checks and balances in group homes, pending the finalisation of the transition plan by:

- enhancing resources to the NDIS Quality and Safeguards Commission
- enhancing powers, if necessary, of the NDIS Quality and Safeguards Commission to undertake proactive spot checks
- rolling out a fully-funded National Official Visitors Scheme, auspiced by the NDIS Quality and Safeguards Commission, with the power to address violence, and proactively prevent further violence occurring
- facilitating DPO-led training to staff in group homes on violence, exploitation, abuse and neglect.

**Recommendation 4** – That an independent statutory national protection mechanism be established to protect, investigate and enforce findings in relation to all forms of violence against people with disability.

**Recommendation 5** – That primary prevention strategies within group homes be developed and implemented during the transition period, aimed at preventing violence and abuse from occurring in the first instance and embedding a culture of safety in group homes for people with disability.



**Recommendation 6** – That funding from the NDIA, for people eligible for Specialist Disability Accommodation (SDA) and Supported Independent Living (SIL), separates housing and support services for people with disability, and further, that such separation be a condition of funding.

**Recommendation 7** – That the following recommendations from the Joint Standing Committee on the National Disability Insurance Scheme's (JSC on the NDIS), *Report into Supported Independent Living*<sup>2</sup> are implemented as a matter of urgency by the National Disability Insurance Agency (NDIA) and the NDIS Quality and Safeguards Commission to drive choice and control for people with disability who are eligible for SIL and/or SDA:

- JSC on the NDIS Recommendation 18
   The Committee recommends that the National Disability Insurance Agency review its existing policies and procedures, to ensure that participants needing assistance with daily living are given genuine choice as to whether they access supports in a shared or individual living arrangement.
- JSC on the NDIS Recommendation 19
   The Committee recommends that the National Disability Insurance Agency give all participants living in congregate settings, who receive Supported Independent Living funding, the opportunity to review their accommodation and support arrangements and to exit the congregate setting if they wish to do so.
- JSC on the NDIS Recommendation 21
   The Committee recommends that additional funding be made available to support participants seeking to exit congregate living arrangements.
- JSC on the NDIS Recommendation 22
  The Committee recommends that the National Disability Insurance Scheme
  Quality and Safeguards Commission implement additional oversight measures
  for participants in group living arrangements.
- JSC on the NDIS Recommendation 24
   The Committee recommends that the National Disability Insurance Agency implement a mechanism to separate service delivery, tenancy management and support coordination for participants in Supported Independent Living settings.
- JSC on the NDIS Recommendation 25
   The Committee recommends that the National Disability Insurance Agency, with the National Disability Insurance Scheme Quality and Safeguards Commission, implement a mechanism to ensure participants accessing Supported

https://www.aph.gov.au/Parliamentary\_Business/Committees/Joint/National\_Disability\_Insurance\_Scheme/Independentliving/Report.



<sup>&</sup>lt;sup>2</sup> Joint Standing Committee on the National Disability Insurance Scheme, Report into Supported Independent Living (2020). Available at

Independent Living are able to change providers without compromising housing security or suffering other adverse consequences.

**Recommendation 8** – That the key role of independent advocacy services in identifying, responding and preventing violence, abuse, neglect and exploitation of people with disability is recognised.

**Recommendation 9** – That long-term and dedicated funding for independent advocacy services is provided.

**Recommendation 10** – That a transition plan is fully resourced and supported.

**Recommendation 11** – That a transition plan includes strategies that address barriers people with disability face in living in non-congregate settings, including:

- capacity building for disability sector collaboration and other key stakeholders
- ensuring individual advocates are empowered to identify and address the root causes of violence
- promoting self-advocacy, self-agency, peer support and advocacy by and for people with disability
- ensuring access to supported decision-making processes where required
- · facilitating informed choice in all settings; and
- ensuring trauma informed support services are appropriately resourced to support people with disability with histories of institutionalisation.

**Recommendation 12** – That a review of all Commonwealth, state and territory laws and policies is undertaken to assess compliance with the *Convention on the Rights of Persons with Disabilities*.

**Recommendation 13** – That the *Homes and Living* inquiry be extended to include other forms of closed and congregate housing, such as residential out-of-home care (including voluntary out-of-home care), boarding houses including Assisted Boarding Houses, rooming houses and hostels, aged care facilities, and current and past large residential facilities.

**Recommendation 14** – That the *Homes and Living* inquiry be extended to include how SDA and SIL frameworks are re-perpetuating practices that lead to forms of violence.

**Recommendation 15** – That new housing programs in cities and regional centres be given a significant funding boost.

**Recommendation 16** – That new housing programs in cities and regional centres model best practice housing for people with disability and therefore contribute to a dynamic mainstream housing market in Australia.



**Recommendation 17** – That all governments be required to develop and implement a plan to make social housing fully accessible.

**Recommendation 18** – That all governments be required to develop and implement a plan to close all boarding houses and rooming houses, and place people with disability currently living in these premises into contemporary, accessible and affordable housing.

**Recommendation 19** – That all new and extensively modified future Class 1a and Class 2 dwellings under the National Construction Code be amended to meet the Gold Level specifications outlined in the Liveable Housing Design Guidelines.



# 3. Drivers of violence and abuse in group homes

#### The 2015 Senate Inquiry highlighted drivers of violence

The extent of violence and abuse toward people with disability in shared accommodation settings was thoroughly documented in the 2015 Report of the Senate Standing Committee on Community Affairs Inquiry into Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability.<sup>3</sup>

As noted in the Senate Committee's report, people with disability experience higher risks of violence and abuse, and in particular, women with disability experience domestic and family violence in a variety of settings, relationships and contexts, including group homes. Sexual assault, abuse, theft and many other issues arise in group homes.

The Senate Inquiry's Terms of Reference provided a usefully broad definition of "violence, abuse and neglect" as including but not limited to:

"... domestic, family and interpersonal violence; physical and sexual violence and abuse; psychological or emotional harm and abuse; constraints and restrictive practices; forced treatments and interventions; humiliation and harassment; financial abuse; violations of privacy; systemic abuse; physical and emotional neglect; passive neglect; and wilful deprivation." <sup>4</sup>

This broad definition encouraged submissions to the Inquiry that explored the drivers of violence experienced by people with disability in congregate housing. PWDA's submission<sup>5</sup> provided a comprehensive analysis of the conceptualisation of violence against people with disability in a human rights framework that remains cogent, and highly relevant to understanding why the extent of violence against people in institutions and congregate housing tends to be underplayed:

"Regardless of setting or context, violence against people with disability in Australia continues to be conceptualised, downplayed and 'detoxified' as 'abuse' or 'neglect' or 'service incidents,' or 'administrative infringements' or a 'workplace issue to be

<sup>&</sup>lt;sup>5</sup> Frohmader, C., & Sands, T. (2015) Australian Cross Disability Alliance (ACDA) Submission to the Senate Inquiry into Violence, abuse and neglect against people with disability in institutional and residential settings'. Australian Cross Disability Alliance (ACDA). Sydney, Australia. Available at http://wwda.org.au/wp-content/uploads/2013/12/ACDA Sub Sen Inquiry Violence Institutions



<sup>&</sup>lt;sup>3</sup> Report of the Senate Standing Committee on Community Affairs Inquiry into Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability. (2015) Available at: <a href="https://www.aph.gov.au/Parliamentary">https://www.aph.gov.au/Parliamentary</a> Business/Committees/Senate/Community Affairs/Violence abuse neglect/Report

addressed'<sup>6</sup> – rather than viewed as 'violence' or crimes<sup>7</sup>. This is particularly the case in institutional and residential settings – including group homes, boarding houses, mental health facilities, schools and prisons – where violence perpetrated against people with disability is rarely recognised or understood as 'violence', and more often than not, is deliberately minimised, trivialised, ignored, dismissed, excused, covered up, or normalised.

"Terms such as 'abuse' are often used in an effort to acknowledge that a power dynamic may be part of an assault. This detoxifies assault. It also exacerbates the existing tendency to infantilise adults with disability, because in a criminal context, 'abuse' is primarily used in relation to children. Similarly, the use of terms such as 'neglect' to describe the withdrawal of, or failure to provide, life sustaining supports is also problematic. It can make situations where the intention is to cause death, appear 'less violent', and this often affects prosecution. It also affirms the narrative found in both media and criminal prosecutions that people with disability constitute such 'burdens' on their carers that this 'burden' mitigates the crime.<sup>8</sup> 'Neglect' of children is a specific criminal offence, but its use in relation to adults can again be infantilising.

"People with disability who live, occupy, and/or experience institutional, residential and service settings are regularly deprived of the information, education and skills to recognise and address violence, and are often taught and 'rewarded' for, unquestioning compliance. They often do not recognise the violence perpetrated against them as a crime and are unaware of how to seek help and support. Even if they are able to disclose, they are unlikely to be believed, and are often actively prevented from seeking help and support. In such settings, criminal behaviours are simply normalised.

"This widespread tendency to downplay and re-frame violence as 'abuse' or as a 'service incident' results in denying people with disability the legal protections and justice extended to other people. Pervasive discriminatory and ableist attitudes within police culture and the criminal justice system (including the tendency to blame the victim; refusal to investigate allegations of violence; treating crimes of violence as a 'service incidents'; failing to make reasonable adjustments; assuming that a prosecution will not succeed because the court may think the person lacks credibility; along with negative or paternalistic stereotypes of people with disability), all contribute to the pervasive and extensive violence perpetrated against people with disability in institutional and residential settings.<sup>10</sup>

<sup>&</sup>lt;sup>10</sup> Frohmader, C., Dowse, L., and Didi, A. (2015) 'Preventing Violence against Women and Girls with Disabilities: Integrating A Human Rights Perspective'. Women With Disabilities Australia (WWDA), Hobart, Tasmania. ISBN: 978-0-9585268-4-5; Frohmader, C. (2011) Submission to the Preparation Phase of the UN Analytical Study on Violence against Women and Girls with Disabilities,



<sup>&</sup>lt;sup>6</sup> French, P., Dardel, J., & Price-Kelly, S. (2010) *Rights denied: Towards a national policy agenda about abuse, neglect and exploitation of persons with cognitive impairment.* People with Disability Australia, Sydney

<sup>&</sup>lt;sup>7</sup> Sorensen, D. (1997) 'The Invisible Victims', IMPACT, 10 (1997), 4–7; Frohmader, C., (2007) 'Forgotten Sisters – A global review of violence against women with disabilities', WWDA Resource Manual on Violence Against Women With Disabilities, WWDA, Tasmania, Australia; Sobsey, R. (1994) 'Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance?' Baltimore: Paul H Brookes Publishing Co; Sherry, M. (2003) 'Don't Ask, Tell or Respond: Silent Acceptance of Disability Hate Crimes

<sup>&</sup>lt;sup>8</sup> Sullivan, C. (2015) 'Not Just Language: An analysis of discursive constructions of disability in sentencing remarks', Honours Thesis Sydney Law School, University of Sydney. See, for example, Clarke, T., (2014) 'Husband Jailed Over Starvation Death' in The West Australian, August 14.

<sup>&</sup>lt;sup>9</sup> Frohmader, Č. (2011). op. cit.

"The lack of a clear conceptual understanding and legal recognition of violence against people with disability in legislation, policy, and service frameworks results in no or low priority being given to the issue within service environments, including in institutional and residential settings<sup>11</sup>, which in turn, serves to perpetuate the systemic violence experienced by people with disability in institutional and residential settings. It also means in effect, that for people with disability – particularly those in institutional and residential settings – their experiences of violence are not properly recognised across the legal and service systems, they are given less protection than their counterparts who do not have disability, and the likelihood of them benefiting from integrated and coordinated responses, including prevention, is substantially compromised.<sup>12</sup>" <sup>13</sup>

In its submission to the Inquiry, Deakin University noted that "where people with disabilities live and the cultures of the organisations that provide services, in particular residential services, are significant factors that impact on risk of violence, abuse and neglect", and that it is the "isolation from broader society and the 'closed' nature of disability services' that can lead to a 'corruption of care'".<sup>14</sup>

#### Grouping of residents for the convenience of providers

As noted in the Disability Royal Commission Group Homes Issues Paper, group homes "refers to accommodation where services and supports (both within the [group] home and the community) are provided to four to six long-term residents with disability. Group homes may include 24-hour on-site staff support."<sup>15</sup>

Under the NDIS Specialist Disability Accommodation (SDA) Rules, large group homes (more than 5 residents) are progressively being phased out. However, without significant reform of the housing arrangements under the NDIS, group homes with five residents or less will continue to be enrolled and approved as part of the NDIS's SDA framework.

There is recognition among disability housing providers and the NDIA that there is opportunity through the NDIS's SDA program for investment in new housing stock that realises independent living in the community for people with disability with high and complex support needs. However, within the SDA program, group homes are continuing to be built as the standard for housing for people with disability who are assessed as eligible for SDA. This represents about 6% of participants in the NDIS.<sup>16</sup>

<sup>&</sup>lt;sup>16</sup> National Disability Insurance Agency (2018) Specialist Disability Accommodation Provider and Investor Brief, April 2018, p. 5.



<sup>(</sup>A/HRC/RES/17/11). Prepared for Women With Disabilities Australia (WWDA); Frohmader, C. & Cadwallader, J. (2014) Joint Submission from National Cross-Disability Disabled People's Organisations (DPO's) to the Senate Standing Committee on Finance and Public Administration 'Inquiry into Domestic Violence in Australia'.

<sup>&</sup>lt;sup>11</sup> Frohmader, C., Dowse, L., and Didi, A., (2015) 'Preventing Violence against Women and Girls with Disabilities: Integrating A Human Rights Perspective' Women with Disabilities Australia, ISBN: 978-0-9585268-4-5.

<sup>&</sup>lt;sup>12</sup> Frohmader, C. & Cadwallader, J. (2014), op. cit.

<sup>&</sup>lt;sup>13</sup> Report of the Senate Standing Committee on Community Affairs Inquiry into Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability (2015), op cit. <sup>14</sup> ibid., Chapter 3, Lived experience of violence, abuse and neglect

<sup>&</sup>lt;sup>15</sup> Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, (November 2019) "Group homes issues paper" p. 2. Available at https://disability.royalcommission.gov.au/publications/group-homes

It is important to recognise that the dynamics that lead to violence do not necessarily diminish when the group home is smaller – violence can in fact be more likely to escalate, with personality clashes, bullying and controlling behaviour (on the part of staff and management, as well as other residents), more readily dominating the lives of people with disability.

Group homes can also limit opportunities for residents to form friendships and support alliances in the wider community. In the words of a PWDA advocate, group homes are sometimes places where "people are just lumped together at random".

The advocate gave the example of two male residents who disliked each other intensely being forced to live in the same house. The home was a "breeding ground for violence and aggression", and this was compounded by a lack of available supports to facilitate better communication between the two men.

These experiences are exacerbated by the lack of choice and control that people with disability have over whom they live with, and who provides support services. Residents are also often grouped on the basis of commonality of high support needs.

This may be convenient and cost-effective for providers working within the NDIS pricing frameworks, but it does not deliver on the objects of the NDIS Act to "enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports".<sup>17</sup>

#### Case study 1: Ezra

Ezra\* has high support needs and lives in a group home. The PWDA advocate noted:

- Unexplained injuries, including one which has resulted in lengthy hospitalisation and impairment
- Use of restrictive practices
- Overmedication
- High agency staff turnover
- Ratios of support that are below specialist recommendations
- Poor communication between house managers and Ezra's family
- Poor maintenance of the house which is often unclean
- Incorrect billing

The advocate is working with Ezra and her family to consider alternative living options, and working with Ezra to explore all available legal options.

\* Name has been changed to maintain anonymity

<sup>&</sup>lt;sup>17</sup> National Disability Insurance Scheme Act 2013, No. 20, 2013, An Act to establish the National Disability Insurance Scheme, and for related purposes, Part 2, Section 3 (e). Available at https://www.legislation.gov.au/Details/C2013A00020



## Restrictive practices as a behaviour management tool leading to systemic violence

Advocates observe the use of a range of restrictive practices by disability support providers as behaviour management tools in institutions and other congregate residential settings such as boarding houses, including:

- forced medication
- solitary isolation or seclusion
- withholding food, money and medication
- restraint
- strip-searches
- bullying and harassment<sup>18</sup>
- over-use of anti-psychotics
- not providing sufficient access to specialist medical services
- not facilitating participation in community.

Restrictive practices are under-regulated and, at times, unregulated in Australia. They are authorised at the state and territory level, but are covered by the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector, <sup>19</sup> endorsed by all Australian governments in March 2014.

The NDIS Quality and Safeguards Commission also has a role in monitoring, responding and providing guidance in relation to complaints regarding the use of restrictive practices by NDIS service providers.

Australia's UN CRPD Shadow Report 2019 observed that:

"The National Framework for Reducing and Eliminating the Use of Restrictive Practices (2014) and the NDIS (Restrictive Practice and Behaviour Support) Rules 2018 have significant limitations and permit States and Territories to authorise the use of restrictive practices. The Framework and the NDIS Rules focus more on when and how to use restrictive practices rather than prohibiting their use".<sup>20</sup>

PWDA advocates note that despite these regulations and safeguards, restrictive practices pervade some group homes and embed high-level, systemic violence, abuse and neglect. Incidents of violence are often denied, silenced, concealed and unreported if regarded by the service provider as a component of restrictive practices.

<sup>&</sup>lt;sup>20</sup> Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities (2019) in response to the List of issues prior to the submission of the combined second and third periodic reports of Australia [CRPD/C/AUS/QPR/2-3]. Compiled by the Australian Civil Society CRPD Shadow Report Working Group, July 2019, Available at <a href="https://dpoa.org.au/wp-content/uploads/2019/08/CRPD-Shadow-Report-2019-English-PDF.pdf">https://dpoa.org.au/wp-content/uploads/2019/08/CRPD-Shadow-Report-2019-English-PDF.pdf</a>, p. 27



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 <sup>18</sup> Frohmader, C. & Sands, T. (2015), Submission to Senate Inquiry into Violence, Abuse and Neglect against People with Disability in Institutional and Residential Settings. Australian Cross Disability Alliance (now Disabled People's Organisation Australia), Sydney, p 35.
 19 National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector – accessible at <a href="https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-framework-for-reducing-and-eliminating-the-use-of-restrictive-practices-in-the-disability-service-sector.</a>
 20 Australian Civil Society Shadow Board to the Using Allating Organisation (2015)

#### Case study 2: Zendaya

Zendaya\* has been living in a Group Home since 2013 as her parents (her previous primary carers) are no longer able to support her due to failing health. Zendaya has been subject to different forms of violence since 2013 as a result of the group home using restrictive practices such as locking the fridge and pantry to deter a co-tenant from eating uncontrollably.

A co-resident blamed Zendaya for these restrictive practices and began biting her. This continued over a five-year period, with no action by the staff to address the violence and provide a safe environment. According to Zendaya's parents, she suffered many problems during this time, and resorted to self-isolation to her room – which included not using the bathroom to avoid the co-resident. Zendaya's "behaviours escalated...she would even defecate in her room rather than face the prospect of another random bite". Zendaya become increasingly fearful and distressed by the violent resident and staff's inaction.

Zendaya's parents estimated that she sustained around fifty bites over nearly six years, along with a range of other injuries. Requests by the parents to provide a safe environment were ignored, and obfuscated by blaming Zendaya's behaviour as justification for the violence. The parents were critical of the responses of the staff, saying that house staff spent their shifts ignoring the problems and sat in the closed, locked office on their computers or phone. At one point they discovered that all of Zendaya's toenails were falling off. Upon investigation it turned out that "the staff left a pair of socks stuffed in her shoes, but her feet had been jammed into them anyway".

Zendaya's parents have attempted over the years to address the violence through internal complaint mechanisms at the group home, which at no point referred the matter to independent advocacy services. Due to language and cultural barriers, Zendaya's parents did not know about the availability of independent advocacy. The parents were finally referred to individual advocacy by their GP, after reporting the situation to their GP as the cause of their failing mental health.

Since seeking the support of an individual advocate, new accommodation has been found, where "Zendaya is happy, calm, cared for and clearly likes the staff". The advocate is continuing to work with Zendaya on developing her living skills and settling her into her new home, as well as working with Zendaya and her parents on exploring what legal action they would like to take.

\* Name has been changed to maintain anonymity

#### Zendaya's case demonstrates that:

 Group home residents can be subjected to ongoing violence over long periods of time without any action being taken. In this case staff inaction and failure to respond to serious and sustained incidents continued for over six years.



- A culture of violence and neglect pervaded the home, with staff failing to respond to Zendaya being attacked and injured by other residents, while at the same time treating her harshly and neglectfully.
- There are inherent problems with a residential model of living which forces people to live together for no reason other than disability.

As noted by the 2015 Report of the Senate Standing Committee on Community Affairs Inquiry into Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability, people with a disability are most likely to be abused in segregated service environments, where abusive practices go unrecognised and unreported and where client and family participation in services is devalued. At the time of writing, the COVID-19 public health restrictions in place across Australia are being used by some group home managers to justify restrictions on residents' movements, with residents in some cases prevented from leaving the residence.

#### Case study 3: Congregate accommodation lock-down

At the time of writing, a PWDA advocate is supporting three group home residents who reside in a house with ten other people.

All residents have intellectual and/or psychosocial disability. The three men have disclosed to the advocate that the group home manager/owner is preventing them from going out "because of coronavirus", and is preventing support workers from visiting.

One of the three men has a psychosocial disability; one an intellectual disability; and the other both an intellectual and psychosocial disability. The advocate advises that:

- 1. The group home manager has locked the only entrance to the property, a gate on the head-high front fence, from the outside.
- 2. Residents have been told that because of COVID-19, they must not go out for any reason, and if they do so they will not be allowed to return; and they will be refused entry, even to collect their belongings. The three men are complying because they are extremely fearful of the threat that they will be locked out, and are convinced that it will be carried out. Each of the men is generally frightened of the house manager/owner at the best of times, describing him as a bully.
- 3. One of the men was allowed to attend a hospital appointment. The house manager drove him to the appointment, but the man had to go home by taxi. He feared that he would be locked out but was allowed back in.
- 4. None of the other residents have been allowed to attend medical appointments, or shop for necessities.



- 5. All support workers are being refused entry, and contact with their client is limited to conversations over the front fence, and passing over shopping, including cigarettes. Each resident chips in an equal dollar amount to get groceries, with apparently no individual billing of items.
- 6. The manager's rationale for locking out the support workers, and refusing re-entry to residents who go out, is that this is necessary to protect residents from COVID-19 risk.
- 7. The barring of support workers means that residents requiring assistance with personal care, showering and hygiene are receiving no support. All three of the advocate's clients require such assistance, and the advocate is certain that the clients' needs are being neglected; that their anxiety levels are "through the roof"; and that they would be missing essential medication or taking incorrect dosages.
- 8. No support workers means that no one is monitoring the residents and their medication, or their mental health and wellbeing. The advocate advises that the support workers routinely check medication blister packs and remind the residents to take prescribed doses. The advocate is concerned that without monitoring, residents will miss doses, risk overdose and potentially mix up their blister packs.

The advocate is extremely concerned for these residents. He has contemplated calling the police for a welfare check, but hasn't done so because of the three residents' fear of reprisal – and the likelihood, in the advocate's experience, that the police would not take the matter seriously.

Even if the police did take the matter seriously, the advocate also fears the residents would have limited options to assist the men anyway. The residents' greatest fear is eviction and homelessness. The advocate has cautioned the manager against the use of unauthorised restrictive practices; and his response was that he'd spoken to his lawyers who checked and advised "it's all fine".

The above case study is an example of the way in which the COVID-19 health crisis is highlighting and exacerbating ongoing situations of abuse and neglect in group homes, with perpetrators using the public health restrictions as justification for heightened restrictive practices – for effectively imprisoning residents, and denying access to support workers.

The advocate involved advises that a complaint will be made to the Australian Human Rights Commission when the men are less frightened of the repercussions, i.e., after the COVID-19 public health restrictions are lifted.

#### Reluctance to change Supported Independent Living providers

Despite the promise of the transformative power of the NDIS, group homes continue to offer little to no choice to people with disability regarding where they live and with whom



they live. These fundamental rights to choice are denied, with decision-making largely made by providers and dependent on the availability of vacancies.

Our advocates on PWDA's Housing Information Line receive calls from people with disability who are unhappy with their Supported Independent Living (SIL) provider and have been told that unless they leave their current housing, there are limited (or no) avenues to change the provider to one of their choice.

For people with disability who are NDIS participants and eligible for Specialist Disability Accommodation (SDA) and SIL to realise choice and control, provision of housing and provision of supports need to be separated. Without this separation, people with disability are more likely to be exposed to ongoing violence, abuse, neglect and exploitation because one provider is in control of all facets of person's life.

The need to separate housing from supports was recognised in the report of the Tune Review of the *National Disability Insurance Scheme Act 2013* (2019), which noted:

"Consultation feedback reinforced contemporary approaches to accommodation for people with disability should, as far as practicable, separate the provision of housing and the support provided in the home."<sup>21</sup>

The report goes on to say this is currently a contested issue in the NDIS and recommends the SIL operational guidelines consider the principles of choice and control.<sup>22</sup>

In addition, the recently released *Joint Standing Committee on the National Disability Insurance Scheme: Report into Supported Independent Living* highlights the increased risks for people with disability of experiencing violence, abuse, neglect and exploitation where a provider delivers both housing and supports through the NDIS's SIL and SDA funding and service delivery arrangements.<sup>23</sup> The report notes:

"The Committee heard that allowing a single entity to exercise control over both tenancy and service delivery may have significant negative impacts for participants, including reductions in service quality; increased risks of abuse and neglect; and reduced housing security. The Committee considers that the NDIA should work to separate tenancy, service delivery and support coordination as a matter of urgency. In addition, the Committee considers that the NDIS Quality and Safeguards Commission must take an active role in enforcing the separation of these functions."<sup>24</sup>

SIL is founded on a principle of shared supports, which thereby limits a person with disability's choice and control over who delivers supports. As noted earlier, shared supports in congregate settings, such as group homes (based on a quotation process from

<sup>&</sup>lt;sup>24</sup> Ibid, xviii.



18

 <sup>&</sup>lt;sup>21</sup> Tune, D. (2019), Review of the National Disability Insurance Scheme Act: Removing red tape and implementing the NDIS Participant Service Guarantee. Canberra (December 2019). Para. 6.74
 <sup>22</sup> Ibid. Recommendation 14

<sup>&</sup>lt;sup>23</sup> Joint Standing Committee on the National Disability Insurance Scheme: Report into Supported Independent Living (May 2020), Canberra, Commonwealth of Australia.

SIL providers) runs counter to the objects of the NDIS Act which aim to "enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports". 25

As stated in the Executive Summary of the recently released Joint Standing Committee on the National Disability Insurance Scheme: Report into Supported Independent Living:

"Evidence suggests that the existing SIL regime may force participants with SIL to live in shared settings, and may be perpetuating older models of disability support rather than delivering the innovations promised by the NDIS".26

PWDA supports the key findings and recommendations of the Joint Standing Committee on the National Disability Insurance Scheme (JSC) in relation to SIL as they point to the urgent need for fundamental reform of the policy and funding arrangements of SDA and SIL within the NDIS. The JSC's inquiry into SIL makes it clear that the current approaches to SDA and SIL are promulgating and perpetuating congregate living arrangements where people with disability are being denied choice about and control over where and with whom they are living with. Furthermore, people with disability who are assessed as eligible for the SDA and SIL are experiencing significant systemic barriers within the NDIS to participating in plan development and reviews and changing service providers when necessary.

In particular, PWDA draws out the following JSC recommendations as they have the potential to mitigate against people with disability's exposure to violence, abuse, neglect and exploitation as a result of being forced to live in congregate settings such as group homes. We propose these are urgent first steps to realise a progressive transition away from congregate living for people with disability.

#### These recommendations are:

#### Recommendation 18

The Committee recommends that the National Disability Insurance Agency review its existing policies and procedures, to ensure that participants needing assistance with daily living are given genuine choice as to whether they access supports in a shared or individual living arrangement.

#### Recommendation 19

The Committee recommends that the National Disability Insurance Agency give all participants living in congregate settings, who receive Supported Independent Living funding, the opportunity to review their accommodation and support arrangements and to exit the congregate setting if they wish to do so.

#### Recommendation 21

<sup>&</sup>lt;sup>26</sup> Joint Standing Committee on the National Disability Insurance Scheme, Report into Supported Independent Living (May 2020), Canberra, Commonwealth of Australia, p. xviii.



<sup>&</sup>lt;sup>25</sup> Op. cit., p.12.

The Committee recommends that additional funding be made available to support participants seeking to exit congregate living arrangements.

#### • Recommendation 22

The Committee recommends that the National Disability Insurance Scheme Quality and Safeguards Commission implement additional oversight measures for participants in group living arrangements.

#### • Recommendation 24

The Committee recommends that the National Disability Insurance Agency implement a mechanism to separate service delivery, tenancy management and support coordination for participants in Supported Independent Living settings.

#### • Recommendation 25

The Committee recommends that the National Disability Insurance Agency, with the National Disability Insurance Scheme Quality and Safeguards Commission, implement a mechanism to ensure participants accessing Supported Independent Living are able to change providers without compromising housing security or suffering other adverse consequences. <sup>27</sup>

We make further recommendations to develop a transition plan to create a full move away from congregate living in Section 5 and Section 6 of this submission.

#### Case study 4: Tim

Tim\* was living in a one-bedroom apartment in a new building of eight SDA apartments. He uses a wheelchair and likes to socialise with friends who live in the city.

The building has a 'recommended and preferred SIL provider' which is attached to the apartments and also provides some property management functions. Tim used this SIL provider for his daily support and was unaware that he had an option to use a different provider.

Tim told PWDA that he experienced neglect and abuse from his first SIL provider.

A few months into his tenancy, a number of service incident reports listing 'behaviours of concern' had been filed against him, including being rude to staff, swearing and making threats. Tim clearly linked his behaviours to his neglect and abuse.

Tim's SIL provider was unable to resolve the problems and he was faced with possible eviction from his home.

At this point, Tim's support co-ordinator intervened and quickly established alternative inhome support from a different SIL provider. Tim engaged in a positive way with the new support worker and his behaviour at the property improved. The SDA provider



<sup>27</sup> Ibid, p. ix-x.

acknowledged that no incident reports had been filed since the new support came on board. As a result, Tim was able to keep his home.

Tim has been developing independent living skills and making choices about his supports and who provides it with advocacy support.

\* Name has been changed to maintain anonymity



# 4. Realising our international human rights obligations

PWDA is a member of Disabled People's Organisations Australia (DPO Australia), an organisational alliance which seeks to advance the rights of people with disability across a range of contexts, including by:

- reporting on compliance with UN human rights conventions; and
- working with government to reform housing policy, promote access to complaint mechanisms, end indefinite detention and address violence against, and the abuse and neglect of people with disability.

Australia is a signatory to the *Convention on the Rights of Persons with Disabilities* (CRPD). DPO Australia was a member of the Working Group that developed *Disability Rights Now 2019: Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities* (CRPRD Shadow Report).<sup>28</sup>

#### Denial of right to adequate housing

The right to an adequate standard of living for people with disability, including adequate housing, is enshrined in **Article 28** of the CRPD. For housing to be adequate a person must have a choice of where, and with whom, they live (**Article 19**).

As outlined in this submission, group homes do not constitute 'adequate housing'. Even if an individual expresses satisfaction with remaining in a particular group home, the absence of the option to move elsewhere if and when issues arise (including extreme and ongoing levels of violence, abuse and/or neglect), means that Article 19 is contravened.

The CRPD Committee on the Rights of Persons with Disabilities has noted that the presumption that people with disability are unable to live independently in the community on an equal basis with others has led to "resources being invested in institutions instead of in developing possibilities for persons with disabilities to live independently in the community".<sup>29</sup>

Supported group accommodation is a form of congregate living which is not the norm in the general community, and the absence of alternative options compels people with disability to live with others in a particular residential setting to receive the support they

<sup>&</sup>lt;sup>29</sup> Committee on the Rights of Persons with Disabilities. *General Comment No. 5 (2018) on living independently and being included in the community* (27 October 2017). CRPD/C/GC/5.



<sup>&</sup>lt;sup>28</sup> Australian Civil Society CRPD Shadow Report Working Group (2019), Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities in response to the List of issues prior to the submission of the combined second and third periodic reports of Australia. Op cit.

require.<sup>30</sup> This perpetuates an accommodation arrangement that is explicitly prohibited in the CRPD, and that goes against the objects of the NDIS Act.

#### Denial of right to be free from violence, abuse, neglect and exploitation

Group homes do not promote or deliver on the right to be free from all forms of violence, abuse, neglect and exploitation enshrined in **Article 16** of the CRPD. As outlined above, people with disability in group homes simply cannot be guaranteed protection from violence, abuse and neglect. Group homes must be phased out, and Australia must develop alternative housing options that centre the needs of people with disability.

Two recent UN human rights reports support our key recommendations to phase out group homes, and develop a transition plan:

- 1. The Concluding Observations on the combined second and third periodic reports of Australia adopted by the Committee on the Rights of Persons with Disabilities at its 511<sup>th</sup> meeting held on 20 September 2019.<sup>31</sup>
- 2. The release of the Special Rapporteur on adequate housing's *Guidelines for the implementation on the right of housing*<sup>32</sup> released at the 43<sup>rd</sup> session of the UN Human Rights Council in March 2020.

## Concluding Observations of the Committee on the Rights of Persons with Disabilities

In 2019, the CRPD Committee made the following two clear recommendations that support the need for a plan to enable all people with disability to live independently in the community. The Committee recommended that Australia:

- a) Develop a national framework aimed at closing all disability-specific residential institutions, including by addressing how persons with disabilities not eligible for the NDIS can be supported to transition from living in an institution to living independently in the community.<sup>33</sup>
- b) Increase the range, affordability and accessibility of public and social housing for persons with disabilities, including by implementing a quota for accessible social housing and by developing regulations and standards to guarantee the progressive application of universal design principles in accessible housing.<sup>34</sup>

<sup>&</sup>lt;sup>33</sup> Committee on the Rights of Persons with Disabilities. *Concluding observations on the combined second and third periodic reports of Australia*. 511<sup>th</sup> Meeting (15 October 2019). Op cit. Para 38(a)
<sup>34</sup> ibid, para 38(b)



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<sup>&</sup>lt;sup>30</sup> Committee on the Rights of Persons with Disabilities. *Concluding observations on the combined second and third periodic reports of Australia*. 511<sup>th</sup> Meeting (15 October 2019). CRPD/C/AUS/CO/2-3

<sup>&</sup>lt;sup>32</sup> UN Special Rapporteur on adequate housing. *Guidelines for the Implementation of the Right to Adequate Housing*, Forty-Third Session, Human Rights Council (24 February – 20- March 2020) A/HRC/43/43

#### The Guidelines of the UN Special Rapporteur on adequate housing

The Special Rapporteur's recently released Guidelines on housing:

- a) Reaffirmed that housing is a component of the right to an adequate standard of living, and that accessing this right must be on non-discriminatory basis<sup>35</sup>; and
- b) Specifically clarifies (guideline No. 8) how countries like Australia must ensure nondiscrimination in implementing the right to housing, by noting that the right to adequate housing has particular meaning for persons with disabilities as the CRPD imposes three 'distinct obligations':
  - i. Accommodation must be reasonable
  - ii. Promote living independently
  - iii. Promote being included in the community.

Article 2 of the CRPD defines **reasonable accommodation** as "any necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms".<sup>36</sup>

Article 19 of the CRPD defines the **right to live independently** as "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",<sup>37</sup> and the **right to be included the community** as "having 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".<sup>38</sup>

PWDA would further like to highlight to the Royal Commission the significance of the Special Rapporteur's guidance that accessing an adequate standard of housing must be on a non-discriminatory basis. Under international law, the right to non-discrimination must be complied with immediately. The standard of equality that Australia must achieve is substantive equality, and not equality of opportunity or equality of outcome.<sup>39</sup> This requires Australia to recognise the pre-existing disadvantage people with disability may face, and so obliges all Governments to take positive actions to overcome disadvantage.

<sup>&</sup>lt;sup>39</sup> Human Rights Committee, General Comment 18: Non-Discrimination (1989), Office of the High Commissioner for Human Rights.



<sup>36</sup> CRPD, Art 2

<sup>&</sup>lt;sup>37</sup> CRPD, Art 19(a)

<sup>38</sup> CRPD, Art 19(b)

## 5. Phasing out group homes

PWDA has been calling for the closure of institutions of all sizes, including group homes, since our founding in 1981, reflecting our long-standing position that people with disability have the right to live freely in the community on equal terms as everyone else, including with choices equal to others.<sup>40</sup>

In PWDA's 2010 Position Paper, *Accommodating Human Rights*,<sup>41</sup> we outlined an Agenda for Action which identified priorities for Governments to fully realise the right to adequate housing for people with disability:

- Close all residential institutions accommodating persons with disability and the re-allocation of resources enabling us to move into community-based housing, based on values of inclusion and participation in the general community.
- 2. Provide people with disability individualised funding to provide control and choice over the resources required to live with dignity in the community. Further, that flexible funding mechanisms ensure we are able to choose where and with whom we will live, and which agencies and support workers we will engage to provide the necessary supports.
- 3. Take immediate progressive action to significantly increase the availability of social support services necessary for persons with disability to live in and be a part of the community (such as personal care, domestic assistance, and daily living skills support).
- 4. Devise and implement complementary and progressive housing strategies that will significantly increase the availability of accessible social housing.
- Collaborate to develop and implement changes to Australian building regulations that will ensure that all future residential accommodation is accessible and adaptable, and that accessibility features are incorporated into any major renovation or redevelopment of existing accommodation.

In 2011, PWDA elaborated on what the right to adequate housing for people with disability looks like, in our *Shut In Position Statement*,<sup>42</sup> proposing government actions to realise the right to adequate housing. Adding to the Agenda for Action above, PWDA called for the following priority actions which remain relevant within the context of the NDIS:

<sup>&</sup>lt;sup>42</sup> Shut In Campaign Committee (2011). 'Shut In Position Statement: Housing and support for people with disability'



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<sup>&</sup>lt;sup>40</sup> French, P. Accommodating Human Rights: A human rights perspective on housing, and housing and support, for person with disability. People with Disability Australia, 2009. Available at <a href="http://www.pwd.org.au/documents/pubs/AccommodatingHumanRights2003.rtf">http://www.pwd.org.au/documents/pubs/AccommodatingHumanRights2003.rtf</a>

<sup>&</sup>lt;sup>41</sup> French, P. (2010), 'Accommodating Human Rights: A human rights perspective on housing and support for persons with disability', People with Disability Australia, Sydney.

- 6. **Provide people with disability with any support they may require to exercise their rights** and obligations under individualised funding arrangements.
- 7. Invest in independent vision-building processes that assist people with disability and their supporters to envision genuine community living options instead of 'contemporary' institutional options.
- 8. Develop in partnership with people with disability, their families and their representative organisations, housing and support policy guidelines and frameworks that ensure that resources, programs and funding allocations, including individualised funding are only provided to implement the rights contained in the CRPD.
- Develop in partnership with people with disability and their representative organisations, comprehensive awareness raising strategies to challenge and overcome attitudes and beliefs that perpetuate segregated housing and support options for people with disability.

#### **National Disability Strategy**

The National Disability Strategy (2010-2020) affirms the need to separate the provision of housing and support services.

#### The Strategy says:

"There is a widespread view that since the introduction of the *Disability Services Act* (DSA) in 1986, control of functions such as support services and accommodation are best separated at some level in people's lives to minimise the potential for conflict of interest and effective control over a person's whole life by the one human service."

However, decades after the introduction of the DSA and the introduction of the NDIS in 2013, many group homes still combine housing and supports and many providers appear reluctant to separate housing and supports.

<sup>&</sup>lt;sup>43</sup> National Disability Strategy (2010 – 2020). Available at <a href="https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020">https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020</a>, p. 44



#### Case study 5: Legal complexity

A PWDA advocate recently had discussions with a group home manager regarding whether an adult resident, an NDIS participant, would be able to choose her own support worker – from a different service provider. A change of provider and a new support worker had been requested as the resident's relative was unhappy with the lack of support given by the housing provider.

Citing general management issues, workers compensation complexities, logistical and workplace health and safety concerns, the manager advised that his group home would not allow staff from another provider to work with any of their clients, saying this would be a "legal minefield".

The manager also said "there was no precedent"; the service had never allowed this in any of their group homes.

This case study demonstrates that "old practices" of shared supports are continuing under the NDIS across Australia.



## Delivering a contemporary, accessible and affordable housing system

#### A transition plan to phase out congregate living

PWDA advocates for a dynamic housing system for people with disability that includes mainstream, specialist and hybrid options which are contemporary, accessible and affordable. The fundamental aim of this approach would be to end congregate forms of living, and facilitate people with disability living independently in the community.

In our 2019 Federal Pre-Budget Submission, with input from the Summer Foundation, National Shelter and the Australian Network for Universal Design, PWDA called for a minimum \$2.7 billion investment in a National Housing Strategy to stimulate a more dynamic housing system for people with disability. In our submission we noted that "much of Australia's housing stock is unaffordable or inaccessible" and that the "policy settings push people with disability into unsafe and unwanted housing, such as group homes or boarding houses". We also noted that the housing system for people with disability was not coordinated across Australia. 45

The lack of investment has resulted in people with disability overly relying on housing assistance to have a roof over our heads. According to the Australian Institute of Health and Welfare:

- 1 in 12 people accessing Specialist Homelessness Services (SHS) have a disability
- 1 in 3 people accessing SHS have a severe or profound disability
- 1 in 6 people access SHS are doing because they're fleeing family or domestic violence
- Of those who access SHS, people with disability are twice more likely to experience repeat homelessness (at a rate of 6% compared to 3% for those without disability); and
- 2 in 5 people accessing social housing have a disability.<sup>46</sup>

These outcomes are unacceptable. People with disability need a dynamic housing system that offers contemporary, accessible and affordable housing options to end congregate living, and promote people with disability living independently in the community.

<sup>&</sup>lt;sup>46</sup> Australian Institute of Health and Welfare (2019), *People with disability in Australia 2019: in brief.* Cat. no. DIS 74. Canberra: AIHW, pp. 14-15.



<sup>&</sup>lt;sup>44</sup> People With Disability Australia (PWDA) (2019), Federal Pre-Budget Submission, Sydney https://pwd.org.au/pbs-2019/

<sup>&</sup>lt;sup>45</sup> ibid, p. 4

We also recognise that the transition plan to end congregate living, through delivering on a dynamic housing system offering contemporary, accessible and affordable housing options, will need to be progressively realised. The transition plan also needs to ensure that it works for all.

- Recommendation 1 That a transition plan be developed to achieve the following outcomes:
  - 1. All congregate housing, including group homes, be phased out urgently and according to a clear target deadline
  - 2. No new people with disability to enter congregate housing, including group homes
  - 3. Proper resourcing is provided to improve contemporary, accessible and affordable housing options
  - All people with disability living in congregate housing be relocated to contemporary, accessible and affordable housing options as a matter of urgency
  - People with disability are provided with the essential supports and services needed to transition from congregate housing to living independently in the community.

We propose the following five principles be adhered to when developing the transition plan:

- 1. Centre the needs of people with disability
- 2. Strengthen checks and balances
- 3. Ensure decision-making control
- 4. Ensure the right policy and legislative settings
- Address structural barriers.



#### 1. Centring the will and preference of people with disability

The transition plan must centre the needs of people with disability. It must have a reasonable timeframe of at least 12-36 months to mitigate against the risk of people with disability becoming homeless or moving from one form of poor quality congregate housing to another. The transition plan must not warehouse people with disability at the expense of expediency. It is crucial that the transition plan and the target deadline is led, implemented and monitored by people with disability.

The transition plan must also recognise that people with disability living in congregate settings often have limited social support as a result of living in segregated, closed, congregate settings. The transition plan could include individual support coordination to identify what current supports, especially community supports, exist.

Recommendation 2 – That a transition plan away from group homes is developed as a matter of urgency, and it is led, implemented and monitored by people with disability.

## 2. Strengthening oversight and accountability to ensure the safety of people with disability

Pending development and implementation of the transition plan, there is an urgent need to take immediate action to ensure that the violence pervading many group homes and other congregate residential settings is treated as violence and responded to appropriately.

- Recommendation 3 That governments strengthen checks and balances in group homes, pending the finalisation of the transition plan by:
- enhancing resources to the NDIS Quality and Safeguards Commission
- enhancing powers, if necessary, of the NDIS Quality and Safeguards Commission to undertake proactive spot checks
- rolling out a fully-funded National Official Visitors Scheme, auspiced by the NDIS Quality and Safeguards Commission, with the power to address violence, and proactively prevent further violence occurring; and
- facilitating DPO-led training to staff in group homes on violence, exploitation abuse and neglect.
- ➤ Recommendation 4 That an independent statutory national protection mechanism be established to protect, investigate and enforce findings in relation to all forms of violence against people with disability.



➤ Recommendation 5 – That primary prevention strategies within group homes be developed and implemented during the transition period, aimed at preventing violence and abuse from occurring in the first instance and embedding cultures of safety in homes for people with disability.

#### 3. Putting people with disability at the centre of decision-making

The transition plan must also centre informed choice, so people with disability can exercise control over decision-making on their supports and needs. This requires people with disability to have access to supported decision-making processes, to ensure the will and preferences of people with disability are at the centre of all decisions. This must start with the separation of housing from the provision of services and supports.

Further, people with disability need to be at the centre of the NDIA planning process. The transition plan must ensure NDIS planners, support coordinators and Local Area Coordinators, are trained to have effective engagement and discussions with people with disability. These discussions must involve considerations that:

- a. some people have had limited access to effective medication management and may be have been on medications such as clozapine and psychotropic medication for the long-term without sufficient medical oversight or review.
- b. some people may have been living in institutions (large and small) for many years and become 'institutionalised', without having had the experience of living in the community. This experience needs to be considered in the provision of appropriate supports for goal setting in plans as well as during the transition to independent living.

Placing informed choice at the centre of NDIS planning will require people with disability to have access to independent advocacy, particularly advocates who have expertise in housing in the community. This should ensure that the will and preferences of people with disability are recognised and heard. Therefore, we recommend:

- ➤ Recommendation 6 That funding from the NDIA, for people eligible for SDA and SIL, separates housing and support services for people with disability, and further, that such separation be a condition of funding.
- Recommendation 7 –That the following recommendations from the Joint Standing Committee on the National Disability Insurance Scheme: Report into Supported Independent Living are implemented as a matter of urgency by the NDIA and the NDIS Quality and Safeguards Commission to drive choice and control for people with disability who are eligible for SIL and/or SDA:
  - JSC on the NDIS Recommendation 18
     The Committee recommends that the National Disability Insurance Agency review its existing policies and procedures, to ensure that participants



needing assistance with daily living are given genuine choice as to whether they access supports in a shared or individual living arrangement.

- JSC on the NDIS Recommendation 19
   The Committee recommends that the National Disability Insurance Agency give all participants living in congregate settings, who receive Supported Independent Living funding, the opportunity to review their accommodation and support arrangements and to exit the congregate setting if they wish to do so.
- JSC on the NDIS Recommendation 21
   The Committee recommends that additional funding be made available to support participants seeking to exit congregate living arrangements.
- JSC on the NDIS Recommendation 22
   The Committee recommends that the National Disability Insurance Scheme Quality and Safeguards Commission implement additional oversight measures for participants in group living arrangements.
- JSC on the NDIS Recommendation 24
   The Committee recommends that the National Disability Insurance Agency implement a mechanism to separate service delivery, tenancy management and support coordination for participants in Supported Independent Living settings.
- JSC on the NDIS Recommendation 25
   The Committee recommends that the National Disability Insurance Agency, with the National Disability Insurance Scheme Quality and Safeguards Commission, implement a mechanism to ensure participants accessing Supported Independent Living are able to change providers without compromising housing security or suffering other adverse consequences.
- ➤ Recommendation 8 That the key role of independent advocacy services in identifying, responding and preventing violence, abuse, neglect and exploitation of people with disability is recognised.
- Recommendation 9 That long-term and dedicated funding for independent advocacy services is provided.

Lastly, choices made by people with disability will face resistance from service providers, support coordinators, Local Area Coordinators, families, carers and other supporters of people with disability. People with disability need these stakeholders to support their choices and understand their choices and preferences. Therefore, we also recommend:

➤ Recommendation 10 – That a transition plan is fully resourced and supported.



- Recommendation 11 That a transition plan includes strategies that address barriers people with disability face in living in non-congregate settings, including:
  - capacity building for disability sector collaboration and other key stakeholders
  - ensuring individual advocates are empowered to identify and address the root causes of violence
  - promoting the self-advocacy, self-agency, peer support and advocacy of people with disability
  - ensuring access to supported decision-making processes where required,
  - facilitating informed choice in all settings; and
  - ensuring trauma informed support services are appropriately resourced to support people with disability with histories of institutionalisation.

## 4. Reviewing the policy and legislative frameworks that perpetuate congregate living

The transition plan must not be encumbered by competing policies, legislation, and legislative requirements. For the transition plan to work, people with disability need the transition plan to be situated within an overarching policy framework that ensures its success. This requires a comprehensive review investigating:

- The drivers that perpetuate outdated models of congregate housing in the NDIS and the broader housing system
- How the scale, speed, and pricing for the SDA roll-out entrenches congregate living as the dominant model for disability housing; and
- Policy and pricing arrangements for a shared support program such as SIL.
- Recommendation 12 That a review of all Commonwealth, state and territory laws and policies is undertaken to assess compliance with the Convention on the Rights of Persons with Disabilities.
- Recommendation 13 That the Homes and Living inquiry be extended to include other forms of closed and congregate housing such as residential out-of-home care (including voluntary out-of-home care) boarding houses including Assisted Boarding Houses, rooming houses and hostels, aged care facilities, and current and past large residential facilities.
- Recommendation 14 That the Homes and Living inquiry be extended to include how SDA and SIL frameworks are re-perpetuating practices that lead to forms of violence.



#### 5. Addressing the structural barriers to accessible and affordable housing in the community

Lastly, there are significant structural barriers that will compromise the success of a transition plan. People with disability need the following two structural barriers to be addressed, if we are to realise the end goal of providing a dynamic housing system that offers contemporary, accessible and affordable housing options for all.

The structural barriers are:

- 1. Affordability
- 2. Market preparedness.

#### **Affordability**

People with disability experience a greater level of poverty, with Australia remaining last out of the 27 Organisation for Economic Co-operation and Development (OECD) countries when it comes to relative poverty risk for people with a disability. 47 This means that 45% of people with disability in Australia live near or are below the poverty line. 48

While housing affordability is an issue for all Australians, the disproportionately high poverty risk for people with disability needs to be considered when addressing the affordability of housing options. Further, our ability to improve our income and economic participation is limited by the compounding barriers we face accessing employment<sup>49</sup> and education. 50.

Therefore, coordinated national government action is required to access the housing people with disability need. To this aim, we recommend:

- Recommendation 15 That new housing programs in cities and regional centres be given a significant funding boost.
- > Recommendation 16 That new housing programs in cities and regional centres model best practice housing for people with disability and therefore contribute to a dynamic mainstream housing market in Australia.
- > Recommendation 17 That all governments be required to develop and implement a plan to make social housing fully accessible.
- Recommendation 18 That all governments be required to develop and implement a plan to close all boarding houses and rooming houses, and place

Available at https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/education-and-skills



Realising our right to live independently in the community

<sup>&</sup>lt;sup>47</sup> Organisation for Economic Co-operation and Development (2014), Society at a glance: OECD Social Indicators, OECD Publishing

<sup>&</sup>lt;sup>48</sup> Australian Civil Society CRPD Shadow Report Working Group (2019). Disability Rights Now 2019: Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities in response to the List of issues prior to the submission of the combined second and third periodic reports of Australia [CRPD/C/AUS/QPR/2-3], July 2019: p.39

<sup>&</sup>lt;sup>49</sup> Australian Institute of Health and Welfare (2019). People with disability in Australia Web Report – Employment. Canberra. Available at https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/employment.

50 Australian Institute of Health and Welfare (2019). People with disability in Australia Web Report – Education and Skills. Canberra.

people with disability currently living in these premises into contemporary, accessible and affordable housing.

#### **Market Preparedness**

People with disability need a market approach that promotes accessible and contemporary housing options. The approach must not be voluntary, and needs to be mandated by governments, as the housing market has demonstrated that it has not been prepared to fulfil voluntary commitments agreed to back in 2010.

In 2010, there was growing concern for the lack of accessible housing by the community sector, and the housing market expressed a strong preference to avoid regulation. As a result, a mechanism called the National Dialogue on Universal Housing Design brought together representatives from:

- all levels of government
- o stakeholders from the ageing, disability and community support sectors; and
- stakeholders from the residential building and property industry.

Together, the National Dialogue had the sole purpose of developing a national market approach to accessible housing through universal design. Through consensus, the National Dialogue agreed to an aspirational target that 'all new homes will be of agreed universal design standards by 2020, with interim targets and earlier completion dates to be determined for some standards'.<sup>51</sup>

In order to assess the progress of achieving these targets, National Dialogue members recommended that a series of ongoing reviews be undertaken at two to three-year intervals across the 10-year period. Flowing from the National Dialogue, the 2010-2020 National Disability Strategy<sup>52</sup> committed to supporting the National Dialogue's agreement and aspirational target as part of its policy outcome of inclusive and accessible communities.

In 2012, the Australian Government provided \$1 million in one-off funding to Liveable Housing Australia (LHA), sponsored by Property Council of Australia (PCA), to implement the strategic plan. By the end of 2014 LHA was no longer viable and eventually resorted to listing assessors and focusing on SDA within the NDIS.

Further, no reviews were done as planned. By 2015, it was apparent that the National Dialogue agreement had failed. The interim targets had not been met and, without government intervention, less than 5% of the 2020 target would be met.<sup>53</sup>

Given that a voluntary market approach failed, people with disability need governments to mandate the market approach, so the market can effectively prepare and allocate resources to the transition plan. Therefore, we recommend:

<sup>&</sup>lt;sup>53</sup> Australian Building and Construction Board, Accessible Housing. 2019; available at <a href="https://www.abcb.gov.au/Initiatives/All/Accessible-Housing">https://www.abcb.gov.au/Initiatives/All/Accessible-Housing</a>



<sup>&</sup>lt;sup>51</sup> Livable Housing Australia (2017), Livable housing design guidelines version 4 (2nd ed), Sydney: Livable Housing Australia.

<sup>&</sup>lt;sup>52</sup> Building Ministers Forum. Communique, October 2017. In: Department of Industry, ed. Canberra: Australian Government; 2017.

➤ Recommendation 19 – That all new and extensively modified future Class 1a and Class 2 dwellings under the National Construction Code be amended to meet the Gold Level specifications outlined in the Liveable Housing Design Guidelines.



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## Appendix 1: Summary of PWDA's advocacy and work that informs this submission

PWDA's work aims to realise the rights of all people with disability to live a life free from violence, abuse, neglect and exploitation.

Many of our programs and projects involve working with people with disability on housingrelated matters. These projects span a range of settings: Assisted Boarding Houses, Social Housing, Specialist Disability Accommodation (older forms of congregate living such as group homes, as well as new housing models that provide independent living in the community for people with high-support needs).

PWDA's activities in this area is summarised below:

#### **PWDA** housing-related work

#### 1. NSW Boarding Houses Advocacy Project

- This project assists people with disability who live in <u>Assisted Boarding Houses</u> across NSW. The NSW Government has funded PWDA to deliver the project since 2002 in recognition of the range of issues that people with disability living in boarding house accommodation can face.
- The project has involved significant and long-term engagement with the boarding house sector, as part of individual advocacy for clients and to effect policy reform via systematic advocacy. Our work with the project includes:
  - providing independent advocacy and information support for people with disability in dealing with boarding house managers and other service providers
  - visiting Assisted Boarding Houses in NSW on a regular basis, and assisting residents to understand their rights and raise complaints when those rights have been breached
  - monitoring residents' living conditions and reporting to the Department of Communities and Justice on regulatory breaches; and
  - o reporting unethical conduct on the part of Assisted Boarding House staff (e.g. restrictive practices, failure to follow procedures for handling complaints, breaches of resident confidentiality, failure to report illness, inadequate accident and emergency responses, failure to properly administer medication and manage infectious diseases, denial of proper food and nutrition).
- Based on PWDA's long-standing experience providing individual and group advocacy with people with disability in Assisted Boarding Housing, PWDA made a submission to the NSW Government's Statutory Review into the Boarding House Act 2012. We called for a transition plan to be developed to progressively close



Assisted Boarding houses and transition people with disability to independent living in the community.<sup>54</sup>

#### 2. NSW Disability Housing Information and Advocacy Service

Funded by the NSW Government, the service provides information and advice to
people with disability living in Specialist Disability Accommodation (SDA). The
service also provides information on dispute resolution processes, including internal
complaints to the SDA or Supported Independent Living (SIL) provider and external
complaints resolution through a Community Justice Centre.

#### 3. National Disability Advocacy Program (NDAP)

Funded by the Commonwealth Department of Social Services (DSS), the program
provides individual advocacy for people with disability across NSW, and in five
Local Government Areas in Queensland. A significant component of PWDA's NDAP
work involves advocating for clients in efforts to secure suitable, safe and
accessible social housing.

#### 4. National Disability Insurance Scheme (NDIS) Appeals Advocacy and Information

 Funded by DSS to provide support and non-legal advocacy to people living in NSW and QLD in appealing decisions made by the NDIA regarding NDIS plans. These appeals can include NDIA decisions on housing goals.

#### 5. Boarding Houses Expert Advisory Group (BHEAG)

 PWDA is represented on BHEAG which provides regular feedback to the NSW Minister for Families, Communities and Disability Services.

#### Housing advisory and advocacy groups

PWDA is funded as a National Disability Representative Organisation (DRO) and an NSW Peak Advocacy Organisation, and participates in:

- the National Disability Insurance Agency CEOs Forum (chaired by the NDIA)
- the Commonwealth Department of Social Services Market Oversights Advisory Group
- the NDIA Specialist Disability Accommodation (SDA) Reference Group.

PWDA's participation in these groups has a strong focus on highlighting the need for the NDIS to improve access to housing, through the potential innovations in Special Disability

<sup>&</sup>lt;sup>54</sup> People with Disability Australia (October 2019) Closing the door on Assisted Boarding Houses: Transitioning to contemporary, affordable and accessible housing for people with disability: Submission to NSW Department of Customer Service (Better Regulation Division) section 105 legislative review of the Boarding Houses Act 2012 https://pwd.org.au/submission-to-the-review-of-the-nsw-boarding-houses-act-2012



Accommodation that will realise choice and control for people with disability and deliver on the goals of living independently in the community.

#### PWDA also participates in:

- the Australian Network of Universal Housing Design
- Homelessness NSW's Coalition for Appropriate Supported Accommodation for People with Disabilities
- the Australian Council of Social Service's Housing and Homelessness Policy Network
- Shelter NSW's Housing and Homelessness Collaboration and Policy Network
- the Summer Foundation's Welcoming Home Advisory Committee.





For individual advocacy support contact the **Wayfinder Hub** between 9:00 am and 5:00 pm (AEST/AEDT) Monday to Friday via phone (toll free) on **1800 843 929** or via email at <a href="mailto:info@wayfinderhub.com.au">info@wayfinderhub.com.au</a>.

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