

#### Women with Disabilities ACT

Submission to the

**Disability Royal Commission** 

Regarding the **Issues Paper on Group Homes** 

March 2020

#### **C** Moore

#### **CEO WWDACT**

Women with Disabilities ACT acknowledges and pays respect to the Ngunnawal and Ngambri peoples, the traditional custodians of the ACT Region, on whose land our office is located. We pay our respects their Elders past, present and emerging. We acknowledge their spiritual, social, historical and ongoing connection to these lands and the contribution they make to the life of the Australian Capital Territory.

Winner 2012 International Women's Day Award, Community Category Winner 2015 ACT Chief Minister's Inclusion Awards, Excellence in Championing Human Rights

### **STRONG WOMEN** STRONG VOICES

www.wwdact.org.au | info@wwdact.org.au | 0468 324 695 | Level 2, 71 Northboune Avenue, Canberra City 2601 | ABN 74 908 530 982



www.facebook.com/wwdact @wwdact



#### **About WWDACT**

Women with Disabilities ACT (WWDACT) is a systemic advocacy and peer support organisation for women, girls, non-binary and feminine identifying people with disabilities in the ACT. WWDACT follows a human rights philosophy, based on the Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on the Elimination of (all forms of) Discrimination Against Women (CEDAW). WWDACT is a Disabled People's Organisation, governed by women\* with disabilities, and its proposals and recommendations to government are consistent with Article 4 (3), and Article 29 of CRPD which outline the imperative for consultation with disabled peoples.

WWDACT, through its membership, has strong links to relevant ACT advocacy organisations such as Advocacy for Inclusion (AFI), People with Disabilities ACT (PWDACT) and the Health Care Consumers Association of the ACT (HCCA). WWDACT also has a close association with the Women's Centre for Health Matters and Women with Disabilities Australia (WWDA), the peak organisation for women with all types of disabilities in Australia.

#### **Background**

WWDACT is seeking to provide through this submission a summary of the research and anecdotal evidence we have gathered from the ACT community to provide perspective on the major issues occurring within Group Homes. We do not name people or organisations, and our evidence is focused on systemic issues. We are particularly concerned about the deprivation of human rights endemic to the group home model, which maintains institutionalised violence against women, girls, non-binary and feminine identifying people with disabilities. Data collection on violence against women\* with disabilities is limited, despite the known prevalence of violence, abuse, neglect and exploitation against them.

The most recent United Nations Outcomes Report on Australia's implementation of the Convention on the Rights of Persons with Disabilities indicated that the Committee was "concerned about: a) The fact that the specialist disability accommodation (SDA) framework facilitates and encourages the establishment of residential institutions and will result in persons with disabilities having to live in particular living arrangements to access NDIS supports;" and recommends that "that [Australia] ... Develop a national framework for the closure of all disability-specific residential institutions". This feedback alone makes it clear that Group Homes violate Australia's human rights obligations.

The term Group Home, is in itself a misnomer. A 'home' is a place where a woman\* lives, with which she identifies and where she feels a sense of belonging. This is not the environment created in many group living configurations. A Group House refers, instead, to the bricks and mortar, to the building in which the woman\* lives. This absence of a feeling that she is part of a 'family' is reflected in the fact that most domestic and family violence legislation does not regard the group home as a family or domestic setting. For many women\* with disabilities the institutional feel of their accommodations is such that the term Group House is used.

#### Questions

Question 2: What is your opinion of the quality of life for people with disability in a group home?

The quality of life for people with disabilities in group homes can be highly variable, depending on their provider, how they are matched with house mates and how much their choices are restricted

<sup>&</sup>lt;sup>1</sup> UN Outcomes Report on Australia, 2019.

in day to day life. Across the board, group homes place limits on the freedoms of people with disabilities, due to routines and rules designed to create efficiencies for staff and reduce the number of staff needed to support people with disabilities. This efficiency and profit-driven approach to care de-prioritises quality of life of people with disabilities and promotes the culture that enables violence, abuse, neglect and exploitation.

Group Homes were intended as a replacement for large-scale institutions and were supposed to allow people with disabilities to live in the community. However, most of them currently function as mini-institutions that isolate residents almost completely from the community outside the home's walls. This includes family members, who have reported to WWDACT that they have been unable to have uninterrupted quality time with family members living in a group home. This is just one example of how the social and psychological needs of residents are placed below the physical needs, resulting in poor mental health, clashes between residents and the use of restrictive practices to control people with disabilities.

The health of residents is compromised in these Group House settings because support staff become the first responders when any health issues arise. Such staff are unlikely to have medical training and become gatekeepers for access to health care. Without good access to the people who might prompt immediate access to doctors (such as family and friends), referrals are sometimes not made or not made in time. This can lead to shortened lifespan for some residents.

# Question 4: When violence, abuse, neglect and exploitation occurs in group homes, what do you think are the causes? What can be done to prevent violence, abuse, neglect or exploitation in group homes?

The causes of violence, abuse, neglect and exploitation in group homes are complex. Some scenarios WWDACT is aware of include:

- Poor staffing ratios leading to the use of restrictive practices to 'control' residents
- Poor screening of staff allowing people with criminal records to become support workers
- Low skill level of staff, and lack of training, so that residents are not understood, their needs
  are consistently not met, resulting in a high level of frustration with consequent behaviour
  that is not understood
- Little understanding or management of group dynamics, leading to violence between residents
- Power imbalances between staff and residents leading to intimidation, abuse and violence
- Gender preferences of women with disabilities being ignored when assigning support workers and housemates
- Lack of choice in routine leading to people with disabilities being 'punished' with abuse.

Many of these issues are linked back to the devaluing of the preferences and rights of people with disabilities, power imbalances between staff and residents, poor staff ratios and a lack of human rights training, including positive behavioural support.

Isolation from the community is often amplified by the group home environment, which is treated as an institution by staff, with strict rules, routines and schedules. This reinforces the power imbalance between staff and disabled women\*, and provides opportunity or violence, neglect and abuse by staff or fellow residents. One of the most effective ways to reduce violence and abuse against women\* with disabilities is to address social isolation. Support plans need to include social activities

that help women\* widen their social circles beyond their forced household. Women\* should also be supported to develop decision-making and self-advocacy skills to help them speak up, and enable them to make choices, which will be best facilitated in a more independent living environment. However, the power imbalance between staff and residents needs to be addressed for women\* with disabilities to be able to assert their rights in a meaningful way.

Systemic prevention strategies should include Official or Community Visitors through which issues of risk could be identified, random spot checks completed of Group Homes, and referrals made to police or reporting bodies as needed. The current Official Visitors Scheme in the ACT has had issues where visitors have been unable to access residences, so they should have increased power and resources to do so, as seen in the Victorian Community Visitors Scheme<sup>2</sup>.

Few mechanisms exist to support interaction of residents as individuals into mainstream social situations. Having women\* with disabilities live in congregate accommodation such as that of a Group House tends to reduce opportunities for the non-disabled community to form friendships, and for women\* to be integrated in the community.

Question 5: Do you consider the experiences of violence, abuse, neglect and exploitation in group homes different for particular groups of people with disability? For example, how does a person's gender, age, or cultural or sexual identity impact on their experiences? What are the experiences of First Nations people in relation to group homes?

Women\* with disabilities experience unique and increased forms of violence and abuse in Group Homes as a result of the intersecting marginalisation of gender and disability. For example, women\* with disabilities in group homes are subject to menstrual suppression or forced contraception which may contribute to increased rates of sexual abuse and violence from both support workers and other residents. One way this can happen is that due to the common practice of menstrual suppression, support workers can check what medication residents are on to find out if a woman is on contraception, and use that fact to target her for sexual abuse, as there is a low risk of pregnancy that could be used as evidence. Women\* with disabilities may also be targeted for abuse due to vulnerability during manual handling, showering, communication difficulties preventing them from reporting and many other factors.

Women\* with disabilities may also have their specific preferences, such as the preference for female staff or housemates, ignored as a matter of convenience. Trauma informed care is not often implemented in group homes, so women\* with disabilities can be retraumatised after abuse. For those who are survivors of sexual assault, a preference for women-identifying support staff may not be respected meaning disabled women are left in triggering situations. For example, a woman who was a rape survivor would often be triggered by having many men standing over her in bed for personal care and manual handling. Because the preferences of this woman were not considered through a gendered and trauma informed lens, she was retraumatised, damaging her mental health and leading to poorer quality of life.

<sup>&</sup>lt;sup>2</sup> Community Visitors, Office of the Public Advocate, 2020. <a href="https://www.publicadvocate.vic.gov.au/our-services/community-visitors">https://www.publicadvocate.vic.gov.au/our-services/community-visitors</a>

## Question 6: Is there a continuing role for group homes in providing accommodation for people with disability? If so, what is the role? If not, what are the alternatives?

WWDACT believes that Group Homes should be phased out as an accommodation for people with disabilities as they are by design not individualised, not flexible to the needs and wants of the resident and are often chosen more for the convenience of support workers and families than the person with disability. This is in line with the United Nations Outcomes Report on Australia's implementation of the Convention on the Rights of Persons with Disabilities<sup>3</sup>.

The UN CRPD supports the right of people to freely choose their place of living (Article 4 [General Obligations], Article 19 [Living Independently & Being Included in the Community] and Article 26 [Habilitation & Rehabilitation]). The right to choose where we live and with whom is echoed in other UN Human Rights conventions and covenants. Mechanisms are needed to support people to live independently or to choose to share accommodation with other disabled and/or non-disabled house mates, in any configuration which is arrived at by choice.

Alternatives to group homes include providing funding to individuals to enable them to choose the supports they need for independent living. This offers more choice, social engagement and may be cheaper for some people than Group Homes<sup>4</sup>. Women\* and their family members who have spoken to WWDACT have said that they would have much preferred an option such as this especially in situations where more than one family member was a disabled person as this allowed them to live together and exercise their choices more freely.

For people who require more specialised housing, Specialist Disability Accommodation (SDA) combined with and appropriate level of independent living supports is a solution that is already being used for some. However, SDA markets are currently subject to severe undersupply issues. There is a chronic under-supply of affordable, accessible housing in Australia. It is very difficult for NDIS participants to be approved for SDA funding, forcing them to remain in inappropriate settings. The situation is even more difficult for those who are not NDIS participants, such as disabled people aged 65+, who may be forced into aged care settings due to lack of support, when they would prefer to age in place.

# Question 7: Are you aware of the use of restrictive practices in group homes that you can share with the Royal Commission? If so, what needs to change or happen to eliminate the use of restrictive practices in group homes?

WWDACT is aware through our membership of incidents of environmental restriction, physical restraint, chemical restraint, menstrual suppression and seclusion that have taken place in group homes in the ACT. Additionally, WWDACT has consulted with the ACT Senior Practitioner for the elimination and reduction of restrictive practices<sup>5</sup> to confirm our anecdotal evidence agrees with their latest data. We strongly encourage the Commission to seek out evidence from the Senior Practitioner regarding restrictive practices in the ACT.

One of the most common restrictive practices is chemical restraint, particularly through use of the drug risperidone, which was recently condemned in the Royal Commission on Aged Care and will be

<sup>&</sup>lt;sup>3</sup> UN Outcomes Report on Australia, 2019.

<sup>&</sup>lt;sup>4</sup> Comparing costs and outcomes of supported living with group homes in Australia, Bigby et al. 2018. https://researchmgt.monash.edu/ws/portalfiles/portal/256885773/256805219 oa.pdf

<sup>&</sup>lt;sup>5</sup>Office of the Senior Practitioner, ACT Government, 2020. <a href="https://www.communityservices.act.gov.au/quality-complaints-and-regulation/office-of-the-senior-practitioner">https://www.communityservices.act.gov.au/quality-complaints-and-regulation/office-of-the-senior-practitioner</a>

subject to regulation reform in the Aged Care Sector<sup>6</sup>. WWDACT strongly recommends that the use of risperidone be subject to stronger regulation across the board.

Too often, in group homes contraception is used without their informed consent, to prevent women and female-bodied people from having periods. WWDACT has also heard from parents who have sought contraception for their child/ren without the individual's consent due to fear of sexual abuse in group homes leading to pregnancy. When done to suppress periods, this is called menstrual suppression and is usually done when service providers assume the person is unable to manage their periods. This is not the least restrictive manner to manage periods and may have physiological and/or medical side effects. Menstrual suppression using long-acting contraceptives, appears to be used more now than forced, non-consensual sterilisation. Much of the time, support workers, doctors and families do not recognise menstrual suppression as a restrictive practice due to its normalisation and the common myth that it is in the best interest of the woman with disability. The Royal Australian and New Zealand College of Obstetricians and Gynaecologists affirms that, "All women, including those with a disability, have the right to make their own informed choices about which method of contraception they use", however little is done to actually support women\* with disabilities to make informed choices about what contraception they use or how they manage their menstruation.

One of reasons there is resistance to the elimination of restrictive practices is that there are not enough practitioners who can create or implement a behavioural support plan. WWDACT supports more training of frontline management staff, allied health professionals, nurses and other related professionals in positive behaviour support, so that behavioural support plans are easier to create and implement. This is crucial for not only reducing restrictive practices, but also reducing violence and abuse between residents in group homes where behaviour has been poorly managed in the past. We also believe that by training support workers in positive behavioural support, the culture of punitive and neglectful behaviour responses will be changed. This needs to be maintained in disability support sector as group homes are phased out.

Question 8: What barriers or obstacles exist for people with disability identifying, disclosing or reporting incidents of violence, abuse, neglect or exploitation? What should be done to encourage investigating and reporting of violence, abuse, neglect or exploitation in group homes when it occurs?

WWDACT has found that many women\* with disabilities are unaware of their human rights with regards to freedom of choice, safety from violence, reproductive rights, and much more. There is a systemic failure to inform women\* of their rights and supporting them to make decisions<sup>8</sup>. This lack of decision-making support, insufficient sex and relationships education, and the normalisation of abuse through restrictive practices and punishments, makes it extremely difficult for people with disabilities to identify abuse and report it as such. Issues identifying abuse are compounded by

<sup>&</sup>lt;sup>6</sup>Response to Aged Care Royal Commission Interim Report, Hunt, G. 2019.

https://www.greghunt.com.au/response-to-aged-care-royal-commission-interim-report/

<sup>&</sup>lt;sup>7</sup>Fertility and menstrual management in women with an intellectual disability, RANZCOG, 2016. https://ranzcog.edu.au/RANZCOG\_SITE/media/RANZCOG-

 $<sup>\</sup>underline{\mathsf{MEDIA/Women\%27s\%20Health/Statement\%20and\%20guidelines/Clinical\%20-\%20Gynaecology/Fertility-and-menstrual-management-in-women-with-an-intellectual-disability-(C-Gyn-10)-Review-July-2016\_1.pdf?ext=.pdf$ 

<sup>&</sup>lt;sup>8</sup> Contraception, Consent, Sexuality and Relationships, Hedley, K. 2019. Women with Disabilities ACT. <a href="https://d35ohva3c1yycw.cloudfront.net/wp-content/uploads/2019/07/01115825/Report-May2019\_FINAL-Compressed.pdf">https://d35ohva3c1yycw.cloudfront.net/wp-content/uploads/2019/07/01115825/Report-May2019\_FINAL-Compressed.pdf</a>

myths in the support sector and legal system which say that women\* with disabilities have abnormal sexual behaviour or commonly lie, which causes them to be disbelieved upon disclosure. The power imbalances at play in group homes also make it easy for women\* with disabilities to be intimidated into silence under threats of punishment or being abused again. Even outside of group homes, WWDACT has found it difficult to get women\* to come forward with their stories due to the fear that service providers will cut off accommodation or support.

When they do report, women\* with disabilities often only have the option of reporting incidents to the home manager, who may be involved in the abuse or have a conflict of interest resulting in covering it up. In some cases, women have been forced into mediation with perpetrators, rather than being able to go to the police or an external reporting agency. Even if they contact an external service, domestic and family violence services are ill-equipped to cope with violence in this context, despite group homes being the domestic environment for many women\* with disabilities. Likewise, many bodies that do handle complaints treat group homes as institutional or service environments and treat criminal incidents as service incidents. This makes it extremely difficult for women with disabilities in these settings to seek help and pursue justice.

Convoluted and confusing reporting pathways also prevent women\* with disabilities from reporting abuse when they finally do come forward. One woman, a NDIS participant, tried to report the abuse occurring in their group home in January 2019 and was told by the National Disability Abuse and Neglect Hotline that they would not take any more NDIS cases. They then directed her to the NDIA. The NDIA responded that there was no way to report the provider and directed her to their fraud line. Mishandling of complaints in this manner erodes the trust of women\* with disabilities in the systems that are supposed to protect them, and more needs to be done to re-establish that trust so women\* with disabilities can report incidents safely and confidently.

### Question 9: Should anything be done to improve or change staffing in group homes to better support the choices and potential of people with disability?

Much is needed to improve the staffing of Group Homes and other disability support services to prevent violence, abuse and neglect of women\* with disabilities. Even more work needs to be done to support the choices of women\* with disabilities within a human rights framework. This will need to carry over to new in-home support arrangements as Group Homes are phased out.

Staffing ratios need to improve drastically in order to stop all neglect in Group Homes and allow residents to live as they choose. Poor staffing is currently a major hindrance to quality in-home supports. For example, one WWDACT member reported that her mother was routinely left in bed until midday, missing breakfast, because there were only enough staff available to help one woman at a time in a three-person home. This woman was often moved last as she was disliked by the staff, and the poor staffing facilitated targeted neglect against her. A home of this kind should have staffing to allow all residents to be fed in a timely manner, move about as freely as possible and live their lives by their own schedule. Poor staffing ratios are also likely to be responsible for the use of chemical restraints at night, so that night shifts may be run as 'sleepover shifts'. Other concerns that were raised with WWDACT included how understaffing might affect evacuations in case of emergency, given that basic tasks could not be done in a timely manner.

Training for staff needs to change to be person-centred and focus on support workers facilitating the life choices of people with disabilities, rather than performing a job in a rigid, efficiency driven manner. Human rights training needs to be a mandatory part of all disability support training,

including gender equity; and positive behavioural support, to support the elimination of restrictive practices. Training for management in disability support organisations also needs to include a focus on handling of complaints in a transparent, trauma informed manner to ensure improvement in safety of services for people with disabilities.

#### **Conclusion**

Management of Group Homes in Australia is structured in a manner that inherently restricts the human rights of residents and entrenches institutional violence and abuse. The violence, abuse and neglect that occurs within the walls of these facilities is symptomatic of power imbalances imposed by a system that places convenience and cost ahead of the autonomy and independence of people with disabilities.

Women\* with disabilities are especially disadvantaged in group homes due to the multiple effects of sexism and disability. This leads to higher rates of sexual violence, emotional abuse, neglect and retraumatisation due to inappropriate responses. The issue of group homes needs to be considered through a gendered lens in order to fully understand how violence, abuse, neglect and exploitation manifests in these environments.