



*W*omenwithdisabilitiesvictoria  
empowering women

**Submission to the Royal Commission into Aged Care Quality  
and Safety**

**September 2019**





### **Publishing information**

This document was prepared by Women with Disabilities Victoria (WDV).

Women with Disabilities Victoria (2019), *Submission to Royal Commission into Aged Care Quality and Safety*, (Melbourne: Victoria).

### **Acknowledgment of country**

Women with Disabilities Victoria acknowledges Aboriginal and Torres Strait Islander peoples as the first inhabitants and traditional custodians of the lands on which we live and work. We acknowledge the traditional owners of the land on which this publication was produced, the lands of the Kulin Nations and pay our respects to ancestors and Elders, past, present and emerging.

### **A note about language**

Many people with disabilities have come to refer to themselves as ‘targeted’ and ‘at risk’ rather than ‘vulnerable.’ This change of language shifts the focus away from a blaming tone towards the victim/survivor – and on to the people who choose to abuse people with disabilities and the social conditions that make this common. This language is reflected in this document.

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## About Women with Disabilities Victoria

Women with Disabilities Victoria is an organisation run by women with disabilities, for women with disabilities. Our members, board and staff live across the state and have a range of disabilities, lifestyles and ages. We are united in working towards our vision of a world where all women are respected and can fully experience life. Our gender perspective allows us to focus on areas of particular inequity to women with disabilities: access to women's health services, gendered National Disability Insurance Scheme (NDIS) services and safety from gender-based violence. We undertake research and consultation. We provide professional education, representation, information and leadership programs for women with disabilities.

We have dedicated particular attention to the issue of men's violence against women with disabilities, due to its gravity and prevalence in our lives. Since 2009, we have had a Senior Policy Officer, funded by the Victorian Government, to focus on violence against women with disabilities. This has been a valuable resource for the community sector and government.

Our representation at the Royal Commission into Family Violence in Victoria (RCFV) contributed to sixteen recommendations with specific disability content, and our representation to the Victorian Parliamentary Inquiry into Abuse in Disability Services resulted in a chapter on gender in the Committee's final report.

In 2014, we published 'Voices Against Violence'.<sup>1</sup> This was the result of a two-year research project with partners Office of the Public Advocate Victoria (OPA) and Domestic Violence Resource Centre Victoria (DVRCV). The seven papers of the project examined the intersecting forms of gendered and disability-based violence experienced by women with disabilities, studying literature, OPA files, legislation, and legislation, and interviewing OPA staff and women with disabilities.

This submission draws on findings and recommendations from these projects, alongside our previous projects, work with other organisations and consultations with women with disabilities.

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<sup>1</sup> D. Woodlock Delanie, L. Healey, K. Howe, M. McGuire, et al, (2014), 'Voices Against Violence Paper One: Summary Report and Recommendations.' Women with Disabilities Victoria, Office of the Public Advocate and Domestic Violence Resource Centre Victoria.



## Executive summary

Women with Disabilities Victoria (WDV) welcomes the opportunity to contribute to the Royal Commission into Aged Care Quality and Safety. This Royal Commission is a real opportunity to reassess Australia's system of aged care and start a national conversation around ageism, ableism, quality of life and respect for older people. It is also a critical opportunity for the many women with disabilities, who are also aged care consumers, to have their voices heard.

Our brief submission focuses on the issues raised by our members who are women with disabilities who are also aged care consumers. Our submission focuses on:

- The need for gender-sensitive aged care services;
- A lack of safe and high quality aged care;
- The high costs of aged care, including the over-changing of fees;
- Disparities and inequalities for women with disabilities who are not eligible for support through the National Disability Insurance Scheme (NDIS) due to age; and
- A lack of understanding of the differences between the aged care system and the NDIS and differing approaches to disability support.

We know that women with disabilities experience high levels of disability abuse, family and sexual violence.<sup>2</sup> Often women with disabilities are invisible, as we experience multiple forms of discrimination and marginalisation. Women with disabilities who are ageing experience the impacts of gender inequality and ableism, as well as ageism (the way that older people are viewed as inherently less valuable and less worthy than younger people). These forms of discrimination multiply and increase the risk of violence for older women.

As a snapshot, older women:

- Are sizeable parts of our communities.<sup>3</sup> The majority of people nationally over age 65 are women; older women make up fifteen per cent (15%) of the national Australian population.
- Are more likely to be living in residential aged care (RAC) facilities.<sup>4</sup>

<sup>2</sup> Krnjacki, L., Emerson, E, Llewellyn G., Kavanagh, A., 'Prevalence and risk of violence against people with and without disabilities: findings from an Australian population based study', *Australia and New Zealand Journal of Public Health*, 2016, 40(1): 16 – 21.

<sup>3</sup> Women's Health Victoria, Spotlight on older women's health and wellbeing. Women's Health Victoria. Melbourne (Spotlight; Dec 2017).

<sup>4</sup> Women's Health Victoria, Spotlight on older women's health and wellbeing. Women's Health Victoria. Melbourne (Spotlight; Dec 2017). In 2015, of the 187,300 people living in residential aged care, over two-thirds (68.1%) were women, see: Australian Bureau of Statistics (ABS), 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, (2015).



- Have high rates of disability<sup>5</sup> and are more likely to report living with a 'severe or profound core activity limitation' than men.<sup>6</sup>
- Are more likely to experience elder abuse.<sup>7</sup>
- Are more likely to live alone, and thus, more likely to experience loneliness or isolation.

Our submission also addresses the experiences of younger women with disabilities in the aged care system. This Royal Commission is an essential opportunity to implement reform that will that also means younger women with disabilities have alternatives to entering aged care settings: accessible, affordable and appropriate housing or accommodation and a better variety of support options.

Overall, we hear from many women with disabilities that they felt that their specific needs and support requirements, as a woman with a disability, was not sufficiently met, or understood, within the aged care system. Women also spoke of high costs, inefficiencies, a lack of meaningful choice and control (particularly those receiving supports in the home through home care packages) and conflicting ideas informing the aged care system and the NDIS. They also spoke of the need for gender-sensitivity; they wanted to be able to trust the person coming into their room in a facility, or their own home.

In response, we recommend the use of an intersectional, gendered-lens and human rights-informed approach to understanding the issues facing the aged care system. We also stress the need for a public health informed response, linked to broader primary prevention of violence against women work. We would hope to see primary prevention of violence campaigns that educate and address the common cultural conceptions and stereotypes about ageing and disability, as well as attention to secondary (early intervention) and tertiary (intervention) activities, aligned with the National Plan to Reduce Violence against Women and their Children 2010 – 2020 and Victoria's Free from Violence strategy. We also support moves towards embracing a strengths-based approach to disability in the aged care sector, influenced by the social model, which sees disability as the result of disabling social structures, not just a person's condition or impairment.

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<sup>5</sup> In 2015, most people living in residential aged care with disability had a physical restriction (88.5%), such as chronic pain or incomplete use of arms or legs, with many also having a psychosocial restriction (73.1%), including memory problems and social or behavioural difficulties. See: Australian Bureau of Statistics (ABS), 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, (2015).

<sup>6</sup> Women's Health Victoria, Spotlight on older women's health and wellbeing. Women's Health Victoria. Melbourne (Spotlight; Dec 2017).

<sup>7</sup> Australian Institute of Family Studies (2016), 'What is known about the prevalence and dynamics of elder abuse?' In: Elder abuse: understanding issues, frameworks and responses Australian Institute of Family Studies, Canberra; cited in Women's Health Victoria, Spotlight on older women's health and wellbeing. Women's Health Victoria. Melbourne (Spotlight; Dec 2017).



## Recommendations

### **Recommendation 1: invest in integrated violence prevention activities and community awareness campaigns that address the combined forces of sexism, ageism and ableism in the community.**

Community attitudes that see women with disabilities as dependent, passive, ignorant or in need of protection must be challenged. Gender equity campaigns with a focus on the combined forces of ageism, sexism *and* ableism, are needed to address and change social and cultural attitudinal behaviors and beliefs, which drive the way that ageing and disabled women are treated.

### **Recommendation 2: increase the amount of accessible and affordable housing options by providing more public housing, establishing Livable Housing Design Gold Level as the minimum accessibility standard for private housing and expand rental affordability schemes.**

There is a severe lack of adequate, secure, accessible and affordable housing. Investment in affordable and accessible housing makes 'ageing in place' possible for the majority of people who wish to age remaining in their home, or in their chosen community. Improved access to housing and minimum accessibility standards are universally beneficial for all Australians, including for people with disability, older people and those with young children.

### **Recommendation 3: improve system integration between the aged care system, health system and the National Disability Insurance Scheme (NDIS).**

Many people receiving aged care support also receive assistance through the health system. Better support, integration and cross-system collaboration between the aged care system, health and the NDIS is needed to prevent gaps and maintain equitable outcomes for women with disabilities.

### **Recommendation 4: address workforce issues for aged care workers, through staffing ratios, career opportunities and increased remuneration.**

The aged care sector, like other female-dominated and care-related industries, consists of undervalued paid work. We recommend the introduction of mandatory minimum staffing ratios as understaffing has been shown to have an impact on the quality and safety of support. Evidence and research also tells us that aged care employees consistently rate a lack of career opportunities as a factor influencing their decision to leave the workforce. Increased remuneration, more career development opportunities and ongoing professional development initiatives are required to retain, support and grow a high performing aged care workforce.



**Recommendation 5: provide workforce development for the aged care workforce to improve understanding of disability awareness and in recognising and responding to violence.**

Workforce development for aged care workers in how to identify and respond to family violence, gender-based violence, elder and disability abuse is necessary, across all levels of the workforce, for improved responses to violence and abuse in the sector. Ultimately, aged care service providers must have greater, enforceable responsibilities to ensure their staff are educated and supported in best practice reporting, recording and responding to violence and abuse. Training should also support the aged care sector to understand disability within a human rights and strengths-based framework and as a social construct.

**Recommendation 6: enhanced employment screenings of aged care workers.**

As recommended previously by the Australian Law Reform Commission (ALRC), we support the creation of improved employment screening processes for aged care services to ensure as far as possible, only those who are appropriately qualified and do not pose an unreasonable risk are placed in aged care support roles. Screening processes in the aged care sector should also be linked up with the Disability Worker Exclusion Scheme in Victoria and safety screening requirements administered under the NDIS Quality and Safeguards Commission.

**Recommendation 7: greater scrutiny of restrictive practices and moves to remove their use.**

Chemical and physical restraint, seclusion and segregation are commonplace in institutional environments – including aged care services - yet are often justified as ‘behaviour management’ or ‘behaviour modification’. We need greater scrutiny of these practices in aged care and meaningful initiatives to reduce and eliminate their use, as exemplified in the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector.

**Recommendation 8: make the publication of accessible and easy to understand information about pricing, staffing levels, revenue and performance of aged care service providers mandatory.**

All information about aged care service providers including pricing, staffing levels, revenue, performance and number of complaints received by regulatory bodies, should be easily accessible (in Plain English and Easy English formats) and publicly available. The information provided by service providers, such as service agreements, are often presented in complex and confusing ways for aged care service consumers. Providing



information in this way raises the risk for older women with disabilities of being exposed to exploitation, coercion or abuse.

**Recommendation 9: improve data collection about the incidence and prevalence of abuse in aged care.**

Data reported publicly by the Department of Health is limited to alleged, or suspected, reportable assaults under *Aged Care Act 1997* (Cth) and restricted to residential aged care settings, capturing a narrow set of information. Person-centered methods of data collection and the public reporting of abuse of people in aged care – including making available data in relation to particular cohorts of at-risk population groups, including people with disability, women, Aboriginal and Torres Strait Islander people, is needed to correct existing data gaps.

**Recommendation 10: increase oversight and regulation of the aged care sector.**

Deregulation and privatisation has not necessarily led to greater efficiency, better service or improved choice and control for older women. Rather, it has often led to greater profits generated from poorer service, with many aged care consumers extremely concerned about over-charging of services. This must be addressed through improved oversight and regulation.

**Recommendation 11: continue to fund advocacy for older persons and initiatives to create the infrastructure to encourage meaningful consumer involvement.**

Advocacy and support for women in the aged care system is necessary so that women can access independent advice and information about their rights and receive support. Like any service, aged care services should also ensure consumer involvement to create user-friendly services, as a matter of best practice.



## Key considerations

### Introduction

Australia's aging population is increasing. The majority of older people over age 65 have a disability, as rates of disability increase with age.<sup>8</sup> Many of those within the aged care system are women, due to women's longer life expectancies. Older women are also more likely than men to report living with a 'severe or profound core activity limitation', (sometimes or always needing help with self-care, mobility or communication).<sup>9</sup> This means older women with disabilities are a large component of those receiving support through the aged care system. ABS findings demonstrate that the vast majority (96.5%) of older residents in aged cared accommodation have some form of disability.<sup>10</sup> Around two-thirds of permanent residents in aged care facilities are women.<sup>11</sup>

Disability and gender are key to understanding the nature of our aging population, an increasing proportion of the national population. Gender and disability significantly affects experiences of ageing. In many ways, disability itself can be thought of as an inherent part of the aging process, which many of us can expect to go through as we age. However, there is a variety of personal experiences of disability, with differences for those who have spent many years living with disabilities, and those who experience it first with an age-related injury or illness. While the aged care system supports those who have acquired their disability through natural aging, the system also supports many older people who acquired a disability prior to the age pension age.

Older women are also a large and diverse population group. We know that Australia's aging population is ethnically and culturally diverse, speaking a range of languages. In 2016, 1 in 3 older people were born overseas, the majority being from non-English speaking countries. Aboriginal and Torres Strait Islander people also experience higher rates of disability and older Aboriginal and Torres Strait Islander people may experience issues accessing culturally safe aged care arrangements. As lesbian, gay, bisexual, transgender, queer, asexual and intersex (LGBTQAI+) people age, they face a variety of challenges in accessing inclusive support, sensitive to their needs.<sup>12</sup> Older women's

<sup>8</sup> Australian Law Reform Commission (ALRC), *Elder Abuse – A National Legal Response* (ALRC Report 131), 2. Concepts and Context, (2017); Australian Bureau of Statistics (ABS), 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2015.

<sup>9</sup> Australian Institute of Health and Welfare (AIHW), 'Older Australia at a glance', (2018).

<sup>10</sup> Australian Bureau of Statistics (ABS), 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2015.

<sup>11</sup> Australian Institute of Health and Welfare, (2007), 'Older Australia at a glance', fourth edition, Cat. No. AGE 52, (Canberra: AIHW).

<sup>12</sup> See for example, Malloy, who describes living in an independent living unit with an aged care provider, where she was forbidden from discussing her sexuality and visiting other residents. SBS, 'Elderly LGBTQI+ aged care residents say they're being forced 'back into the closet'', accessible at: <<https://www.sbs.com.au/news/the-feed/elderly-lgbtqi-aged-care-residents-say-they-re-being-forced-back-into-the-closet>>.



experiences of ageism, ableism and sexism, does not always look the same, but is a whole of community concern.

### Violence against people with disabilities

Violence and abuse of people with disability is systemic. Violence is driven by negative attitudes and stereotypes, grounded in discrimination against people with disabilities. Violence against people with disability is ultimately the result of those who chose to abuse their power over people with disabilities.

Those responsible for violence may be providers of care in a private setting (such as an intimate partner, or a family member in the home) or in a service setting (for example, staff, managers or volunteers). Disability-based violence involves a diverse range of behaviours that includes impairment-related violence and abuse, physical, sexual, emotional, economic, reproductive violence, ongoing neglect, the use of constraint or restrictive practices and **institutional violence**.<sup>13</sup>

Over the past five years, the ABC, through two Four Corners episodes and a Lateline report, has exposed evidence of the patterns of violence and abuse experienced by people with disability. In 2015, a Senate Inquiry found widespread rates of violence and abuse against people with disability and recommended the establishment of a specific Royal Commission. The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability has been established to inquire into and report on this violence. However, it has long been recognised by Disabled Peoples Organisations (DPOs) and people with disabilities, that institutional settings are some of the most dangerous places for people with disabilities.

Despite successive policies of deinstitutionalisation, many people with disability continue to reside in or work in institutions, or settings with institutional characteristics, closed off from the rest of the community. Often institutional environments, such as education, the justice system, the health system and the aged care system, that are entrusted with supporting people with disabilities are the places that can often be dangerous to us.

### Violence against women with disabilities

Violence against women with disabilities must be understood in the context of the intersections between gender and disability. **Violence against women and disability-based violence** combine to increase the risk of violence against women with disabilities.

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<sup>13</sup> Sources for studies that discuss perpetrators' use of physical, sexual, emotional, economic and reproductive violence and hate crimes can be found in L. Healey, 2013, *Voices Against Violence Paper 2: Current Issues in Understanding and Responding to Violence against Women with Disabilities*, Women with Disabilities Victoria, Office of the Public Advocate and Domestic Violence Resource Centre, Melbourne, [www.wdv.org.au](http://www.wdv.org.au).



The most prevalent form of violence experienced by all Victorian women is family violence. Family violence includes a range of controlling behaviours such as financial abuse, isolation, continual humiliation, psychological abuse, threats to harm children, injury and death.<sup>14</sup> In comparison to women without disabilities who experience violence and abuse, women with disabilities are:

- Less likely to receive appropriate support services;
- More likely to be homeless and live in insecure and unsafe housing;
- More likely to experience physical, psychological and sexual violence, in custodial, residential and health care settings;
- Are more targeted by men and others who use violence;
- Less likely to be believed and less likely to see justice delivered; and
- More likely to be exposed to sexual and reproductive control, such as through chemical and physical restraints.

Women with disabilities also face other additional, systemic inequalities when compared to men with disabilities. Women with disabilities are more likely to be unemployed, have primary caring responsibilities and be effected by poverty and homelessness.

Although the high prevalence of violence against women with disabilities in Australia has been the subject of numerous United Nations (UN) and civil society reports into human rights violations,<sup>15</sup> the violence, abuse and neglect we often experience is not often well understood within the wider community. The 2013 National Community Attitudes towards Violence against Women Survey (NCAS) showed that only 4 in 10 Australians was aware of the greater risks of violence experienced by women with disabilities.<sup>16</sup>

### **Violence against older women**

In Australia, older women are a spiking group within our homeless population and research findings suggest this is due to experiencing family violence.<sup>17</sup> However, older

<sup>14</sup> Australian Bureau of Statistics (ABS), Personal Safety Survey Australia, Canberra, (2016).

<sup>15</sup> See: Australian Human Rights Commission, (2012), Visit of the UN Special Rapporteur on Violence Against Women: Australian study tour report, Australian Human Rights Commission, Sydney; Human Rights Law Centre, (2014), Torture and Cruel Treatment in Australia: Joint NGO Report to the United Nations Committee Against Torture, Human Rights Law Centre, Melbourne; S. Browne, (2012), How have global services addressing violence against women with disabilities understood their needs and what are the lessons for the next generation of practice?, The United Nations Women, Global Virtual Knowledge Centre to End Violence against Women and Girls; Disability Rights Now: Civil Society Report to the United Nations Committee on the Rights of Persons with Disabilities, (2012), compiled by Disability Representative, Advocacy, Legal and Human Rights Organisations, Australia.

<sup>16</sup> VicHealth, (2014), Australians' attitudes to violence against women: Findings from the 2013 National Community Attitudes towards Violence Against Women Survey (NCAS), Victorian Health Promotion Foundation, Melbourne, Australia.

<sup>17</sup> The number of older women accessing homelessness services is increasing, the main reasons older women seek assistance often relate to domestic and family violence, housing issues and financial difficulties. Australian Institute of Health and Welfare, AIHW Specialist Homelessness Services Collection Data Cubes 2011–12 to 2017–18, Findings



women tend to be invisible in the broader discussions about family violence and violence against women.

‘Elder abuse’ is a term used for framing the violence older people experience. ‘Elder abuse’ can also include psychological abuse, physical abuse or neglect, sexual abuse, financial abuse and chemical abuse. The World Health Organisation (WHO) defines elder abuse as actions that are either intentional or unintentional, and can occur within any relationship where there is an expectation of trust, which causes harm or distress to an older person.<sup>18</sup> Recent data provided by Seniors Rights Victoria, showed that the Seniors Rights Victoria helpline, which takes calls about elder abuse, had received a 35% increase in the number of calls over the past three years.<sup>19</sup>

The 2016 Victorian Royal Commission into Family Violence found that elder abuse is an under-reported and unrecognised form of family violence. Although ‘elder abuse’ can be perpetrated by anyone in a position of trust, often the abuse is intergenerational, perpetrated by family members, such as adult children (with sons being perpetrators to a greater extent than daughters)<sup>20</sup> or spouse or partner, making elder abuse also a form of family violence.<sup>21</sup> The experience of family violence in older age can also be part of a continuation of a lifelong pattern of spousal abuse.<sup>22</sup>

There is a serious lack of reporting of violence and abuse by older people.<sup>23</sup> Research findings tell us that those experiencing elder abuse may ‘put up’ with violent situations in order to maintain relationships, as they may be socially isolated or may not identify what they are experiencing as violence or abuse, or not know where to seek help.<sup>24</sup> Older women may prefer not to report violence when perpetrators are partners and family, such as children, fearing that their family members will receive criminal sanctions or police contact. A fear of losing relationships, isolation or the threat of nursing home placement,

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based on use of data from 2017–18 (accessed 13 February 2019), cited in Australian Human Rights Commission (AHRC), ‘Older women’s risk of homelessness: background paper’, (2019).

<sup>18</sup> World Health Organisation (WHO), ‘A global response to elder abuse and neglect: building primary health care capacity to deal with the problem worldwide: main report’, (2008), p. 1.

<sup>19</sup> Seniors Rights Victoria, (2019), ‘Older, Better, Together: A Network Approach to Preventing Elder Abuse Before it Happens’.

<sup>20</sup> Kaspiew, R., Carson, R., & Rhoades, H. (2015). Elder abuse: Understanding issues, frameworks and responses. Melbourne: Australian Institute of Family Studies. p. 8.

<sup>21</sup> Australian Law Reform Commission (ALRC), Elder Abuse – A National Legal Response (ALRC Report 131), Executive Summary.

<sup>22</sup> Cramer, E., and Brady, S. (2013). Competing values in serving older and vulnerable adults: Adult protective services mandated reporting and domestic violence programs. *Journal of Elder Abuse and Neglect*, 25(5), 453–468; Mann, R., Horsley, P., Barrett, C., & Tinney, J. (2014). *Norma’s Project: A research study into the sexual assault of older women in Australia* (ARCSHS Monograph Series No. 98). Melbourne: Australian Research Centre in Sex, Health and Society, La Trobe University; United Nations Department of Economic and Social Affairs. (2013). *Neglect, abuse and violence against older women*. New York: United Nations cited in Kaspiew, R., Carson, R., & Rhoades, H. (2015). *Elder abuse: Understanding issues, frameworks and responses*. Melbourne: Australian Institute of Family Studies.

<sup>23</sup> Australian Human Rights Commission (AHRC), Dr. Kay Patterson, ‘Domestic violence and older people’ speech, (2017).

<sup>24</sup> Joosten, M., Vratsidis, F. and Dow, B. (2017) *Understanding Elder Abuse: A Scoping Study*, Melbourne: University of Melbourne and the National Ageing Research Institute, p. 11.



or a need to enter the aged care system itself, can also act as a form of coercion and creates many barriers to older women accessing safety.

### Two Lives, Two Worlds

Two Lives, Two Worlds, a study funded by the Office of the Status of Women in 2000, interviewed older female victim/survivors about what stopped them from leaving an abusive relationship. They said things, like:

- *“I do not want to lose my house.”*
- *“I can’t leave because my (adult) children do not want me to break up their inheritance.”*
- *“My financial situation stops me leaving because I do not have superannuation and would only have a pension with no house and no other money.”*
- *“I am too old and weak to leave now.”<sup>25</sup>*

**Older women with disabilities sit at the intersection of disability-based violence, violence against women and elder abuse. This multiplies the risk of violence, abuse and neglect for many women in the aged care system.**

### Case study – Emma’s experience

*“Emma<sup>26</sup> lives in Melbourne and identifies as having several disabilities, including hearing loss and a neurological condition. Emma is in her 60s. Emma grew up with violence in her family, as her father was abusive towards her mother, and sexually abused her brothers. Emma has been married twice, and both men were violent. Emma has three children from her first marriage. Her second husband sexually abused her son; he also sexually abused her granddaughter. Emma now supports people with a disability who are victims of crime.”*

Emma’s story demonstrates how older women with disabilities can have experiences of multiple forms of abuse, from multiple perpetrators over their lifetime. The Victorian Royal Commission into Family Violence found that women with disabilities experience many types of violence at higher rates, with increased severity and often for longer than other women.<sup>27</sup>

<sup>25</sup> Australian Human Rights Commission (AHRC), Dr. Kay Patterson, ‘Domestic violence and older people’ speech, (2017).

<sup>26</sup> See: Voices Against Violence, Paper 6: Raising Our Voices – Hearing from Women with Disabilities’, p. 24.

<sup>27</sup> State of Victoria, Department of Health and Human Services, (May 2016), ‘A discussion paper of the Victorian State Disability Plan 2017-2020’, p. 9.



## Institutional violence within the aged care system

Institutional violence takes place in institutional and congregate settings, such as hospitals, group homes or in residential aged care accommodation.<sup>28</sup> Institutional violence and abuse usually involves rigid regimes, poor quality care, unethical or unauthorised practices in response to 'behaviours of concern' or mental ill health needs. This understanding of violence and abuse is well documented in the literature on disability and disability-abuse.

Institutional violence is often experienced over long periods and can be perpetrated by multiple perpetrators, co-residents within an institution, and/or those providing support. Women with disabilities experience institutional violence in the aged care system through:

- Medication mismanagement;
- The overuse of psychotropic medications and excessive use of sedation and restraint (including antipsychotics, antidepressants and sedatives);
- Issues caused by a lack of food safety;
- Repeated requests for assistance not seen in timely manner;
- Poor wound management; and
- Violence, including from staff, family members and co-residents. This also includes sexual violence or harassment.

Aged care workers have spoken out about the over-reliance on sedation and chemical restraints within the residential aged care. The Royal Commission has already heard that up to eighty per cent (80%) of dementia patients were taking a form of psychotropic drug, which can also place people at a greater risk of death, stroke, disability and pneumonia.<sup>29</sup> This over-reliance of restraints and poor quality care is indicative of, or a form of, institutional violence.

Although the *Aged Care Act 1997* (Cth) provides compulsory reporting provisions for aged care workers, aged care workers may not always feel confident in responding to violence, or have the time and support from their workplaces, to identify all the risks and warning signs that a resident or older woman is experiencing violence. Upper level management of aged care services must be held to account for failures to report and correct situations of institutional violence, abuse and neglect. Stronger complaints mechanisms, coupled

<sup>28</sup> International Network of Women With Disabilities, 2010; M. Saxton, M.A. Curry, L.E. Powers, S. Maley, K. Eckels and J. Gross, 2001, 'Bring My Scooter so I Can Leave You: A Study of Disabled Women Handling Abuse by Personal Assistance Providers', *Violence Against Women*, 7, (4), 393–417; G. Hague, R. Thiara, P. Magowan and A. Mullender, 2008, *Making the Links: Disabled Women and Domestic Violence*, Women's Aid Federation of England, Bristol, UK; and C. Frohmader, 2007, *Forgotten Sisters – A global review of violence against women with disabilities*. Women with Disabilities Australia (WWDA) resource manual on violence against women with disabilities, WWDA, Tasmania.

<sup>29</sup> The Guardian, 'Almost 4,000 assaults reported in Australian nursing homes last year, inquiry told', 18 Feb, 2019. Accessed on 06 June 2019, accessible at <<https://www.theguardian.com/australia-news/2019/feb/18/almost-4000-assaults-reported-in-australian-nursing-homes-last-year-inquiry-told>>.



with a prevention focus are essential to address violence, abuse and neglect *before* it occurs.

Whistleblowing in institutional environments is particularly difficult when a workplace context consists of generally low remuneration, understaffing and where staff management can be authoritarian or hierarchical. Staffing shortages and ‘cultures of secrecy’ may deter from taking appropriate actions, (such as the proper investigation and termination of staff) when there has been a disclosure of violence.

Staff need to be supported by their organisation’s management and organisational culture to raise suspicions internally for consideration and investigation, without fear of individual repercussion or reprisal. All aged care providers should have clear, internal policies and processes in place directing how management are to respond, including the provision referral and support pathways for women with disabilities who have experienced violence. We encourage that service providers, policies and guidelines also employ empowering and person-centered language that recognises the strength and credibility of older women with disabilities by using the word ‘disclosures’, rather than ‘allegations’ in policies and guidelines.

Additionally, as reported in the Australian Law Reform Commission (ALRC) Elder Abuse inquiry, there is no publicly available, comprehensive data on the rates of abuse of people receiving aged care. Data reported publicly by the Department of Health is limited to alleged or suspected reportable assaults under *Aged Care Act 1997* (Cth) and restricted to residential aged care settings, capturing a narrow set of information.<sup>30</sup> More rigorous data about abuse of people in aged care should be collected and made publicly available. Important factors like whether an assault involved intersecting, at-risk population groups and cohorts must be part of data collection in order to fill currently existing data gaps. All data made available should be disaggregated by gender.

### **Sexual violence and mandatory reporting in the aged care system**

Currently, the *Aged Care Act 1997* (Cth) legally requires compulsory reporting of alleged and suspected reportable assaults (including unlawful sexual contact and unreasonable use of force) occurring within residential aged care facilities. Reports are required to be made to local police and the Department of Health. While mandatory reporting policies are put in place with the best of intentions, mandatory reporting has the potential to go against a victim/survivor’s express wishes. Mandatory reporting also puts those it seeks to protect in a different position to other victim/survivors who make their own decision about whether or when to report to police or other authorities.

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<sup>30</sup> See: Australian Law Reform Commission, (2016), Elder Abuse Discussion Paper 83 (DP 83), Chapter 11: Aged Care, p. 198.



The *Aged Care Act 1997* (Cth) mandatory reporting requirements allow aged care providers discretion in reporting assaults in cases where the perpetrators are other residents. This applies in cases where the other resident has a cognitive or mental impairment (such as dementia), where care arrangements are put in place to manage the behaviour, or when previous reports of the same or similar incident(s) were previously made to the police. Investigations and charges by police are rare against those who have perpetrated sexual assault against women victim/survivors in residential aged care; especially so if a woman has a cognitive disability, such as dementia.<sup>31</sup>

However, violence from co-residents is a form of institutional violence and has the potential to be widespread and under-recognised. If a woman is experiencing violence at the hands of a co-resident with a cognitive or mental impairment, it is the perpetrator and not the victim/survivor, who should be required to move into temporary accommodation, be re-relocated, or have otherwise arrangements made for, as part of creating new arrangements to prevent further violent or harmful behaviour. Directions, guidelines, and trauma informed training should provide guidance for workers on best practice responses to violence that is both gender-sensitive and trauma informed, including options for support and referral to services, such as sexual assault counselling support.

Generally, research demonstrates that the sexual assault of older women is widely under-recognised in Australian society and is under-reported. The literature review from the Australian report, Norma's Project, a major study into the sexual assault of older women in Australia, found that the available literature indicated that disabilities such as cognitive impairment, physical frailty and other physical impairments, social isolation and reduced control over one's life can provide a heightened risk of abuse. The study found that there are a number of situational risk factors in care settings (like residential care) that contribute to sexual assault including:

- A decreased likelihood of assaults being detected and responded to;
- A lack of formal follow-up due to few mechanisms in place and safeguards;
- Barriers to disclosure of violence due to cognitive or communicative impairment, psychosocial disability, physical disability, delays in police investigation; and
- The way the judicial system and police deals with and understand 'evidence'.<sup>32</sup>

Studies of perpetrators of sexual assault against older women also suggest offenders' motivations also include:

- Impulsive and 'opportunistic' motivations with little planning;
- Sexual gratification;
- 'Pervasive anger' i.e. violent lifestyle generally; and

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<sup>31</sup> Mann, R., Horsley, P., Barrett, C., and Tinney, J. (2014), Norma's Project, *Australian Research Centre in Sex, Health and Society*; also cited in Senior Rights Victoria, 'Elder Abuse, Gender and Sexuality', p. 53.

<sup>32</sup> *ibid.*



- A result of a vindictive outlook, i.e. anger towards women.<sup>33</sup>

Survey respondents in the study Norma's Project reported that a diagnosis of dementia provided another avenue for the denial and avoidance of disclosed or suspected sexual assaults. Additional issues such as workloads, staffing ratios and inadequate staff training were identified as major factors that were limiting organisational responses and follow-up to sexual assault.<sup>34</sup>

### Case example – 'Aged care home carried on 'business as usual' and ignored sexual assault of resident, family says'<sup>35</sup>

*"Dorothy Major was too frightened to press an emergency buzzer for help. The man who had just sexually assaulted her was a nurse, and she worried he might return if she called for help."*

*"It was a male agency nurse, rather than her usual carer, who carried out the assault."*

*"I told her [what happened] and she said, 'I'll have a talk to him, he shouldn't do that, he's not allowed', or something," Mrs. Major said. "She said, 'we'll get rid of him'. He was still there I believe, a week later."*

Dorothy, an older woman and wheelchair user in a residential aged care, who requires regular support, was not provided any support or referrals after being sexually assaulted by a nurse. Her perpetrator was not addressed and her family were not informed of the assault. Dorothy's experience shows that there is a need for improved cultures and training around best practice when reporting and responding to violence in the aged care system.

### The Power Project

The Power Project website provides information around the prevention and reporting of the sexual abuse of older women.<sup>36</sup> It was launched in 2018 at the National Elder Abuse Conference in Sydney. It provides an online resource and aims to raise community awareness about the sexual abuse of older women and assist in prevention.

<sup>33</sup> Ramsey-Klawnsnik, H., Teaster, P., Mendiondo, M., Marcum, J., and Abner, E. (2008). Sexual predators who target elders: Findings from the first national study of sexual abuse in care facilities, *Journal Of Elder Abuse and Neglect*, 20(4), 353-376; Teaster, P., Roberto, K., Duke, J., and Myeonghwan, K. (2001). Sexual Abuse of Older Adults: Preliminary Findings of Cases in Virginia, *Journal of Elder Abuse and Neglect*, 12(3-4), 1-16; Schhiamberg, L., Barboza, G., Oehmke, J., Zang, Z., Griffiore, R., Weatherill, R., von Heydrich, L., and Post, L. (2011). Elder abuse in nursing homes: An ecological framework, *Journal of Elder Abuse and Neglect*, 23(2), 190-211, cited in Norma's Project, (2014).

<sup>34</sup> *op. cit.*, p. 33.

<sup>35</sup> ABC News, 'Aged care home carried on 'business as usual' and ignored sexual assault of resident, family says', 15 April 2019, accessed 13 June 2019, <<https://www.abc.net.au/news/2019-04-14/aged-care-sexual-assault-dorothy-major/10917524>>.

<sup>36</sup> The Power Project, (2016), Opal Institute (part of the Celebrate Aging Program). Accessed on 13 June 2019, accessible at <<https://www.opalinstitute.org/power-project.html>>.



However, there is currently no central information portal in Australia on preventing or responding to sexual abuse of older women. The Power Project provides a list of services that can assist older women who have been sexually assaulted and provides information on compulsory reporting in residential aged care and other educational resources.

### **Women with disabilities' experiences with home care packages**

The Home Care Packages programme assists older people to remain at home for longer by receiving services and supports in the home. In speaking to us, women with disabilities with a home care packages have told us they were frustrated with:

- An overall lack of understanding, awareness and sensitivity around disability and gender – some women spoke about feeling that they do not feel comfortable or trust the people coming into their home to provide support;
- The high administration fees, and the concern that their packages were being taken advantage of by aged care service providers;
- Poor communication on behalf of the aged care provider, especially for women with communication difficulties, including blind, vision impaired and deaf women;
- Inaccessible information about providers, a lack of clear information on performance, profits and transparent reporting;
- Delays in provision of services (sometimes waiting three weeks after requesting services or workers not showing up);
- That the response through available complaints systems has been inadequate;
- That the attitude of service providers was a belief that aged care is all that is need for an aging woman with disabilities; and
- Long waiting times for requests for services to be actioned, for scheduling in support workers, late services, or receiving no services at all.

Some women with home care packages specifically spoke to us about their concerns around high and unreasonable costs charged by service providers. Some reported instances of aged care providers withdrawing funds from a consumer's package, even when they could not get in contact with the consumer. One woman also reported service providers ignoring medical advice and recommendations obtained through her doctor, in regards to the items and services it was recommended she purchase through her home care package.

Women speak about the inaccessibility of the system, its complexity and the added difficulties in navigating it, as women with disabilities. As it exists, the aged care system consists of a complex variety of services, both residential aged care, aged care packages and many types of service providers. Information provided by aged care service providers



can often be inaccessible and confusing, for example, long service agreements full of legal jargon.

The Home Care Packages programme, like the NDIS, is informed by a market and consumer-driven service delivery model. Although this model promises greater personalisation and choice, in practice, many aged care consumers speak of inflexibility and an overly complex system, with more choice for providers, rather than for themselves as consumers of services. Recent research specifically shows that for personalisation schemes, like the NDIS, a consumer's ability to exercise choice and control is not equally distributed; people with disabilities who are socio-economically disadvantaged, are female, are living in rural areas, can make them less likely to be accessing the NDIS.<sup>37</sup>

As Council of the Aging (COTA) have pointed out, markets themselves are not a level playing field, and aged care service consumers are likely to face multiple barriers to effectively exercising their 'choice', especially when the service they are purchasing is an essential social or human service.<sup>38</sup> In a market and consumer driven environment, consumers who experience multiple forms of disadvantage are likely to experience difficulty navigating new markets and consumer relationships. As has been observed in relation to navigating the NDIS, factors that drive inequalities, such as age, gender, socio-economic status, geographic location and household structure, work to constrain potentials for meaningful choice and control.<sup>39</sup> In practice, older women with disabilities are more likely to be negatively impacted by stereotypes about gender and money, especially if navigating disadvantaged exploitive, substandard or inappropriate service relationships.

### **The need for accessible, secure and affordable housing**

*“There are barriers to accessible, affordable housing, accessible, affordable transport, to employment... I think there are probably more barriers to social inclusion than I can know.”*

*“My social life used to be visiting friends and family. Now (with a disability) I'm isolated and alone. Homes aren't universally designed. If I want to see people they have to come to me. Public buildings are a bit more accessible. But homes are where a lot of socialising happens.”<sup>40</sup>*

<sup>37</sup> Malbon, E., Carey, G. & Meltzer, A. (2019), 'Personalisation schemes in social care: are they growing social and health inequalities?', *BMC Public Health*, 19:805.

<sup>38</sup> Council of the Aging (COTA) Australia, (2017), Submission to Productivity Commission Inquiry into introducing competition and informed user choice into Human Services: Part 2, p. 5.

<sup>39</sup> Warr, D, Dickinson, H, Olney, S, et. al. (2017), *Choice, Control and the NDIS*, Melbourne: University of Melbourne, p. 46.

<sup>40</sup> Above are survey responses from Victorian women with disabilities, used to inform Women with Disabilities Victoria's submission to the Victorian Parliament's Family and Community Development Committee Inquiry into Social Inclusion and Victorians with a Disability (February 2014).



Nationally, the number of people receiving home care packages has increased by eighty four per cent (84%) over the last ten years. This reflects an increasing preference for most people to remain living independently, or with assistance, in their chosen communities as they age. Despite this strong preference to remain in one's own home and despite 'aging in place' being a recognised policy objective in the 1997 Aged Care Reforms,<sup>41</sup> there are high levels of concern that there is not enough community-based support and inadequate housing. In reality, many older people can be faced with little choice in deciding where they age.

Research demonstrates that 'ageing in place' policies can be more problematic for multiply disadvantaged groups, such as older people with intellectual disabilities, who are more likely to have poor or unstable housing conditions and higher support needs.<sup>42</sup> For example, many people with intellectual disabilities can experience a mid-life disruption in their living situation, and may live in a group home as they age or may move prematurely to residential aged care. People with disabilities generally are more likely than people without disabilities to live on low incomes and are more likely to have limited accessible housing options, making them more at risk of living in poor and inadequate housing. In general, most housing is not designed with the needs of older people and people with disabilities in mind. The current housing system does not meet the needs of an ageing population or people with disabilities.

For older women specifically, we know that they:

- Live on lower incomes, fewer assets and have less superannuation;
- Are less likely to own their own home;
- Are experiencing increased rates of homelessness – a key contributing factor for this is family violence; and
- Are more likely to be institutionalised (including being placed in residential aged care) than men with disabilities.

However, there is a lack of accessible homes available for purchase, and a lack of accessible and affordable rental properties and adequate accommodation. For women with disabilities, accessible housing must also feel safe. Extra criteria for women with disabilities can include factors that influence feelings of safety and security, such as a good lighting in the building's surrounds and well-lit areas at night, proximity to public transport and other public amenities.

Housing is an important part of a person's wellbeing. The provision of more affordable, accessible, secure and safe housing, including public housing, is essential to ensuring

<sup>41</sup> Australian Institute of Health and Welfare (AIHW), Gibson, D., Rowland, F., Braun, P. & Angus, P., (2002), Ageing in place: Before and after the 1997 aged care reforms. AIHW Cat. No. AUS 26. Canberra: AIHW.

<sup>42</sup> Bigby, C. (2008). Beset by obstacles: A review of Australian policy development to support aging in place for people with intellectual disability. *Journal of Intellectual and Developmental Disabilities*, 33 (1), 1-11.



that older women with disabilities can live quality lives, free from violence, abuse and neglect and stay connected to their communities. Housing is a recognised human right and at WDV, we hear consistently from women with disabilities that issues of poverty and insecure housing have some of the biggest impacts on their health, wellbeing, quality of life and ability to live safely away from violence.

There is also a range of population-level social and economic benefits to providing increased, accessible housing options. The adequate provision of housing can support an ageing population (with raising rates of age-related disability), to remain in their homes, chosen community, or in a location that suits their needs, and enables a reduction in the costs associated with the aged care system.

Minimum accessible standards for housing are also universally beneficial for everyone, not just for those with disabilities, for those with young children and those who are aging. That is why we strongly recommend that a key piece of aged care reform must include the further investment in accessible public housing stock, resourcing and expansion of affordable rental schemes and the adoption of minimum accessibility standards in the National Construction Code (NCC) to enable the aging in place policies to become a reality. We would strongly encourage the Royal Commission to look at activities and reports by the Australian Network for Universal Housing Design (ANUHD).

### **Younger women with disabilities in aged care**

Throughout our submission, we have mostly talked about the aged care system as older women with disabilities experience it. However, there are many younger women with disabilities currently living in aged care nursing homes. Younger women with disabilities are entering aged care facilities as the result of the failure and lack of integration between, other systems, such as the housing and health system. This Royal Commission and the introduction of the NDIS are both important opportunities to put an end to young people entering and living in residential aged care due to a lack of other suitable options.

Young people in nursing homes are people under the age of 65 living in, or at risk of entry into, aged care facilities. Nationally, young people with disability presently occupy five per cent (5%) of all residential aged care beds.<sup>43</sup> They are most likely to enter the aged care system after experiencing an injury or through progressive neurological disabilities, after release from hospital and while still requiring high levels of support.

Young people with disabilities continue to enter nursing homes because of the lack of appropriate alternative housing and accommodation. Overall, evidence shows that young people experience poor health outcomes in the aged care system and increased

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<sup>43</sup> Young People in Nursing Homes National Alliance, Frequently Asked Questions. Accessed on 17 June 2019. Accessible at <<https://www.ypinh.org.au/resources/faqs>>.



social isolation. The Council of Australian Governments (COAG) has previously acknowledged that aged care services are not best designed to meet the needs of younger people with disabilities, which can include rehabilitation support. Younger women entering nursing homes are also more likely to have their caring responsibilities, for partners or children, disrupted while they reside in aged care nursing homes.

This issue highlights the real need for more affordable and accessible private rental, public housing as well as community-based accommodation and support options for young people with complex or high support needs. We echo the statements of many other advocacy groups and Disabled Peoples Organisations (DPOs), including Young People in Nursing Homes (YPINH), emphasising the need for more choices in accommodation and for creating a support system that enables young disabled Australians with high and complex health and support needs to access the support they need.

### Lydia's story

*"I'm Lydia. I am 46 and I have a 26-year history of multiple sclerosis (MS). I have been living in an aged care nursing home since 2013. Prior to being admitted, I was in hospital for treatment of my MS. Prior to this long period of hospitalisation, I was employed part-time as a medical practitioner and lived alone in an apartment.*

*I am the youngest person in this nursing home. There is one other young person. I used to visit her for a short period most days. I stopped visiting this other resident, after approximately one year, as she kept stating that she wanted to die. I found her depressed mood and attitude difficult to deal with. She told me that my reasons for not visiting her any longer were "fair enough".*

*The other nursing home residents are very friendly. However, they speak little English. Most speak dialects of Italian, being Italian immigrants. I have studied Italian at high school and for eighteen months at the nursing home with a tutor. I can greet other residents and say a number of other Italian phrases. Anyway, that is fine. The staff speak English. A number of staff also speak Italian.*

*I discovered two facts at dinner, in the dining room, on the first night. First, I decided the food seemed to be okay. Second, I decided that I would eat all future meals in my room. I found being in the dining room was too difficult due to the language barrier. I arranged quickly with the kitchen manager to have a salad sandwich and a piece of fruit at lunchtime. I avoid soup and dessert with lunch and dinner as I wish to avoid weight gain. I also never eat the morning tea and afternoon tea provided by the nursing home, again to avoid weight gain. I have a variety of snacks in my room, mainly nuts and chocolate bars (of which, I attempt to eat sparingly).*

*I occupy my time with many different activities. I strongly believe that it is important to keep active, thinking and interacting with others to avoid depression. I have a desktop PC*



*and an iPad. I watch TV when I eat my lunch and I watch AFL Football and in the evening. I go out for meals with family and friends. I am an MS Ambassador and undertake public speaking engagements. I have written a short book, called 'In My Room', which is self-published on Amazon Australia Kindle. The book is a detailed A to Z of the objects, people, technology and practices that help me cope as a young person in a nursing home.*

*An NDIS representative recently asked me if I would like to move somewhere more age-appropriate. I am happy living in this facility. I feel safe. I know that I can get assistance reasonably quickly, if I require it. The staff at the home are very friendly and professional. I have no issues with the way that they use the standing and lifting machines with me. They are courteous and respect my wishes.*

*It would be excellent if there was one person, or a few people, within the Department of Human Services who specifically dealt with young people in nursing homes. Young people often have different, specific needs compared to elderly residents. Young people may have small children.”*

### **Molly's story**

*“...I am 18 and was told my only option was to move into a nursing home. As a child, I was able to walk, run, ride and swim like other children. However, when I was 12 years old, my physical condition began deteriorating to the stage where I was unable to sit up without support and I became dependent on others for my care. At this point, I was diagnosed with an early onset progressive neurological disease.*

*When I was 17, I had a severe episode, and was admitted to a private hospital. Although I continued to have a bright and active mind, my physical condition worsened during this time to a point of functional quadriplegia, with the use of one hand only.*

*After one month, I was stabilised and was ready to be discharged. As my father does not live with us, my mother had always looked after me. However, I now needed much more support than mum could help me with, and I could not leave the acute rehabilitation unit of the hospital until this care was arranged.*

*I sat in the hospital for 12 months before disability services assessed my case and approved an adequate disability support package. This however was not very helpful as they said they did not actually have these funds to allocate to me!*

*In the meantime, I was sitting in hospital with nothing to do, taking up a bed that could have been used by someone who actually needed it! The cost of staying in hospital was much more than I needed for a support package! During this time, my mum took unpaid leave from her full-time job to visit every day, while she tried to navigate the complicated disability system to find a solution.*

*We were told at this stage that the only option I had was to move into a nursing home. We were shocked. We decided that we would tell our story to the media. Soon after this,*



*I was offered a place in a supported unit. Although this looked to be a great solution, we had to think about some important considerations. Some of these issues were:*

*Does the support provider have expertise in supporting my particular high and complex needs? What about my ongoing rehabilitation needs? Can they provide transport and access to rehabilitation, acute care and other allied health and clinical services? Is there adequate case coordination to manage the links between health and disability services? Can they accommodate my community and social activities to assist me in leading an enjoyable and fulfilling life? Am I compatible with other residents? These people are going to be my neighbours and housemates after all.”*

You can read more about Molly’s experience on the Young People in Nursing Homes National Alliance [website](#).

### **The aged care system and the NDIS**

In regards to the NDIS, women with disabilities frequently speak to us about:

- The divergent principles and understandings of disability in the aged care sector and the NDIS;
- That the NDIS age eligibility requirements creates disparities and inequalities;
- A lack of understanding of the NDIS within the aged care sector; and
- Limited support and information for people making a decision about whether to receive support through the NDIS, or the aged care system.

There are currently approximately 4.3 million Australians aged between 16 - 65 with disability. At full scheme, 460,000 Australians will be participants in the NDIS, which equates to roughly ten percent (10%) of all people with a disability nationally. This means that most people with disabilities in Australia will not meet the NDIS access criteria. NDIS eligibility criteria requires individuals to have a ‘permanent’ and ‘significant’ disability, as well as being under the age of 65, at the time of applying to enter the scheme.

While the NDIS receives a considerable amount of public attention, it is not the only system that supports people with disabilities. For those currently supported through the NDIS, they will have the option to remain within the scheme, or receive support through aged care services, once they turn 65. As of January 2019, all people with disability aged 65 and over, who were not previously NDIS participants, will access support through the aged care system. A large amount of people will have to turn to the aged care system to access the disability-related support they need in later life.

At present, significant gaps and inequalities within the NDIS are emerging, for example, women with disabilities only make up thirty eight per cent (38%) of all NDIS participants. Culturally and Linguistically Diverse (CALD) and Aboriginal and Torres Strait Islander people are also experiencing inequalities in accessing the NDIS at expected rates. This



may mean that, for many women with disabilities, they may be more likely to be relying on the aged care system for disability support needs as they age. For the significant proportion of women disabilities unsupported by the NDIS, it is vital that arrangements within the ongoing aged care system will work for them as they age. Appropriate disability supports should be available in the aged care system, in a timely and equitable manner, including adequate access to needed assistive technologies.

The development of approaches to cross-sector service coordination and policy collaboration between the aged care system and the NDIS will be essential for older women with disability to experience continuity of care and equitable outcomes. We recommend embedding collaborative arrangements between a range of programs and portfolio areas such as health, disability, aged care, housing and the NDIS, in order to achieve this.

### **Understandings of disability in the aged care sector**

Due to the successes of the disability rights movement, the disability services sector has made some moves towards embedding a strengths-based and rights-informed understanding of disability. This approach is modelled around respect for the principles and rights enshrined in the Convention on the Rights of Persons with Disabilities (UNCRPD). We have heard from women with disabilities that they do not feel that the aged care sector shares this approach to disability, particularly disabilities that arise with aging, such as dementia. As summed up by a participant at a workshop held by Council of the Aging (COTA) in Melbourne this year, the:

*“[I]language used in the broader disability sector focuses on independence, participation and inclusion – it’s about what you can do with supports in place. But, the way disability is framed under aged care sector is very negative and based on principles of frailty and ageing. It’s about decline.”<sup>44</sup>*

This may partly be a result of the fact that Australia’s aged care system does not provide equity of support and lacks expertise in specialist disability support.<sup>45</sup> Many older people with disability, who acquire disability or who need specialist disability support and are not currently receiving this support through the NDIS, or who chose to be supported in the aged care system, may be relying on an aged care system not designed for them and their specific needs.

<sup>44</sup> Council of the Aging (COTA), (2019), ‘What we want in aged care – perspectives from older Victorians to the Royal Commission into Aged Care Quality & Safety’, p. 5.

<sup>45</sup> Disabled People’s Organisations Australia (DPOA), (2016), “Building a Disability Inclusive Australia”, Election Policy Platform.



Any upskilling and training for aged care workforces should support the aged care sector to understand disability, including dementia and cognitive disabilities, within a human rights and strengths-based framework and as a social construct, with a focus on this education being co-facilitated by those with lived experience.

### Addressing workforce issues

Applying a gender-lens also means recognising that Australia's aged care workforce is a predominately female-dominated, older and an undervalued workforce. Negative perceptions of aged care work, as an occupation with both low pay and status remain.<sup>46</sup> The aged care workforce faces a range of industrial issues and workforce challenges such as understaffing, high workloads, high levels of work-related stress, poor conditions, a lack of career opportunities and low remuneration. Workforce issues are not just a concern for aged care sector staff. Working conditions and workforce challenges have an impact on those they work with, people receiving aged care services.

Evidence shows that there is a need to invest in the aged care system and to develop and expand its workforce, as the demand for aged care services is set to increase over time.<sup>47</sup> Evidence and research tells us that aged care employees consistently rate a lack of career opportunities as a major factor influencing their decision to leave the workforce. Increased remuneration and ongoing professional development initiatives are required to retain, support and grow a quality aged care workforce to meet demand.

There is currently a range of mechanisms to regulate for quality in aged care services, including quality of care standards and rules, accreditation processes, complaints mechanisms and Charters of Rights for aged care service consumers. However, understaffing is consistency cited as a common issue that prevents the workforce from performing well. The introduction of mandatory minimum staffing ratios, with a skills mix should be introduced, as understaffing has an impact on the quality and safety of support workers are able to provide. Minimum staffing ratios with the right mix of specialist knowledge and skill levels, increased pay and opportunities for skill development and further development for staff are reform options that must be implemented as part of this Royal Commission's recommendations for reform.

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<sup>46</sup> Australian Government, Department of Health, '2016 National Aged Care Workforce Census and Survey – The Aged Care Workforce', (2016).

<sup>47</sup> By 2013, in Victoria, almost 1 in 4 Victorians will be over age sixty. Victorian Council of Social Services (VCOSS), Delivering Fairness, (2019), VCOSS Budget Submission, 'Chapter 9: Inclusive communities for people with disability, older people and carers'. Accessed 28 May 2019.



## Conclusion

Any comprehensive reform to the aged care system must engage with and centre the consumers of aged care services. Women with disabilities, both young and old, make up a substantial amount of those receiving aged care services and supports, and require equitable and affordable access to the services they need. Women with disabilities report a lack of gender-sensitive aged care services and are at more likely to be targeted for violence due to multiple forms of disadvantage. Gender equity campaigns with a focus on the combined forces of ageism, sexism and ableism, are needed to address and change social and cultural attitudinal behaviors and beliefs over the long term.



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