Submission to the

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

by the Victorian Disability Services Commissioner

June 2020

Authorised by:

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We acknowledge the Traditional Owners of country throughout Australia and recognise their continuing connection to land, waters, and culture. We pay our respects to their Elders past, present and emerging.

About the Disability Services Commissioner

The Disability Services Commissioner (DSC) is a Victorian independent oversight body resolving complaints and promoting the right of people with disability to be free from abuse. We work under the *Disability Act 2006* (the Act).

Our complaints service is free, confidential and accessible. Most complaints are finalised through resolution, but the Commissioner can also conciliate or investigate a complaint. Disability service providers are also compelled to report annually to our office on the number and types of complaints that they receive and how these complaints are resolved.

Through a Ministerial Referral made under s 128I(2) the Act, we also investigate matters relating to the provision of disability services identified in incident reports received from the Department of Health and Human Services (DHHS). This includes deaths, and major impact incidents of assault, injury and poor quality of care. The State Coroner and the Community Visitors Board also refer matters to us.

The purpose of our inquiries and investigations is to identify issues in disability services and develop service improvements in response to those issues. Following an investigation, we can provide a Notice to Take Action to a service provider, or a Notice of Advice to all service providers and to funding bodies and regulators, to help improve the safety and quality of disability services. We report on the outcomes of our investigations to the Minister, the Secretary of DHHS, and in some cases the State Coroner and the NDIS Quality and Safety Commission (the NDIS Commission).

The Commissioner's oversight jurisdiction of service providers is predicated on service providers being registered under the Act. The Commissioner does not have jurisdiction over unregistered providers. Many formerly registered providers are becoming unregistered. This is because they have transitioned to funding under the National Disability Insurance Scheme (the NDIS) and are subject to the oversight of the NDIS Commission. While our oversight role will gradually decrease over 2020/2021, we will continue to ensure quality, safeguarding and oversight mechanisms are in place for people outside the NDIS who are provided residual disability services by the Victorian Government.

Contents

Introduction

All forms of violence, abuse, neglect and exploitation against people with disability, in all settings, is abhorrent and cannot be tolerated. Governments, organisations and community have a critical role to play in preventing and better responding to violence, abuse, neglect and exploitation of people with disability.

There have been a number of public enquiries into the violence, abuse, neglect and exploitation of people with disability in disability services.[1] These inquiries have identified negative social attitudes and daily instances of people with disability being segregated, excluded, marginalised and ignored.[2] Of concern is that people with disability themselves considered disability services as a barrier to, rather than an enabler of, their participation in society. For example, they considered that supports were under-resourced, unavailable, unaffordable, or of poor quality and little benefit.[3]

The Disability Services Commissioner (DSC) has reviewed and investigated too many cases where people with disability have been abused, assaulted, neglected, and otherwise badly treated. People with disability and their families and representative organisations have also highlighted the problematic aspects of the environments in which they live. We therefore welcome the establishment of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission).

Our participation to date with this Royal Commission has included our broad support for the draft Terms of Reference, production of data and documents in compliance with the Notice to Produce issued to our office, the Commissioner's witness statement and appearance at the Homes and Living hearing in Melbourne (2019),[4] and the Commissioner's Plain English summary of his statement, published following that hearing.[5]

Our office has identified overarching themes that have shaped our recommendations in this submission. First, it is our experience that decisions made for and about people with disability can reflect attitudes and practices that are disabling. Therefore, cultural change in relation to how disability is perceived is urgently needed. We consider a whole of community approach is necessary to effect change in laws, policy and education to cultivate a culture of human rights and inclusion of people with disability.

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1. Enquiries include the Australian Government's National Disability Strategy Consultation Report *Shut Out: The experience of people with disabilities and their families in Australia* (2010) (the *'Shut Out Report'*); the Parliament of Australia's Senate Standing Committee on Community Affairs (2015) *Report on the inquiry into abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*; the Victorian Ombudsman's (2015) *Reporting and Investigations of Allegations of Abuse in the Disability Sector: Phase 1 – The Effectiveness of Statutory Oversight; and the Parliament of Victoria's (2015) Inquiry into Abuse in Disability Services.*
2. The *Shut Out Report* 3.
3. Ibid 4.
4. Arthur Rogers (21 November 2019) *Witness Statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.*
5. Disability Services Commissioner (12 February 2020) *Summary of the witness statement of Arthur Rogers to the Royal Commission – Plain English* (Web Page) < https://www.odsc.vic.gov.au/2020/02/12/royal-commission-statement-plain-english-summary-available-now/>.

Second, disability service providers have increasingly moved away from institutional and segregated approaches to service provision, yet many demonstrate a lack of capacity to offer high quality supports and safe environments to people with disability. We recommend a strong focus on workforce training and education, and consideration of more diverse and culturally appropriate housing models. Such action is essential to prevent violence, abuse, neglect and exploitation of people with disability before it starts.

Third, our office considers that regulation and oversight of the disability sector is critical to activating sector-wide responses to violence, abuse, neglect and exploitation of people with disability. While the NDIS Commission offers a nationally consistent approach to quality and safeguarding, there is further need to give primacy to the voices, experiences and knowledge of people with disability. This should occur not only via complaints processes, but also in relation to incident review and investigation procedures, and through enhanced access to Community Visitors and independent advocacy.

Fourth, it is imperative to look beyond the disability sector and ensure disability inclusive policy alignment across areas of housing, health, justice, education, employment, and so on. Rather than focus on disability from a siloed perspective, we have included cross-cutting recommendations for governments and civil society to ensure that mainstream services are also accountable for promoting the equal and active participation of people with disability in the community.

The structure of this submission, including the ordering of recommendations, is organised according to the terms of reference set forth by the Royal Commission. Based on knowledge drawn from our years in the disability sector and our understanding of issues relating to abuse and neglect of people with disability, we have a number of recommendations for the Royal Commission about what should be done to:

- prevent, and better protect, people with disability from experiencing violence, abuse, neglect and exploitation — term of reference (a) as covered in section 2.

- achieve best practice in reporting and investigating of, and responding to violence, abuse, neglect and exploitation — term of reference (b) as covered in section 3.

- promote a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation — term of reference (c) as covered in section 4.

- address intersectional issues and specific experiences of violence against, and abuse, neglect and exploitation of people with disability, including the particular situation of First Nations peoples — term of reference (g) as covered in section 5.

- support families, carers, advocates, the workforce and others in providing care and support to people with disability — term of reference (h) as covered in section 6.

Recommendations

Recommendation 1:
A national framework for the closure of disability-specific residential institutions, including group homes, that do not meet the requirements of the Convention on the Rights of Persons with Disabilities or that do not comply with all domestic laws that apply, including those in relation to the *National Disability Insurance Scheme (NDIS) Act*.

Recommendation 2:
The full incorporation of the *Convention on the Rights of Persons with Disabilities* into domestic law, including through the development of a national Human Rights Act.

Recommendation 3:
Strengthening of human rights legislation in relation to the responsibilities of public authorities. In Victoria, this should include clarification and education around who is a public authority under the *Victorian Charter of Human Rights and Responsibilities*.

Recommendation 4:
Develop and establish a new ten-year National Disability Strategy, directed by an Office of Disability within a central agency such as the Department of Prime Minister and Cabinet, to monitor progress and oversee implementation of the new Strategy.

Recommendation 5:
That the new National Disability Strategy incorporates clear, measurable goals and timelines for implementation of those goals; mandatory action plans for all levels of government and disability service providers; regular public reporting processes; and additional resources to achieve desired outcomes.

Recommendation 6:
Establish permanent consultation mechanisms for the active engagement of people with disability and their representative organisations in the development, implementation and review of the new National Disability Strategy and disability inclusive policies.

Recommendation 7:
Person-centred practice – Education and training of disability staff in person-centred planning and the implementation of Active Support. The NDIS Commission should consider the circumstances in which this training be mandated and the adequate provision of education and training should be reflected in the NDIS pricing arrangements.

Recommendation 8:
Communication supports – Education and training of disability staff to ensure people who require communication supports are assessed annually by a speech pathologist and have a detailed communication plan implemented. The NDIS Commission should consider the circumstances in which this training be mandated and the adequate provision of education and training should be reflected in the NDIS pricing arrangements.

Recommendation 9:
All governments should provide all information in accessible formats, including plain-English formatting, captioning, Australian Sign Language (Auslan) and Braille.

Recommendation 10:
Positive behaviour supports – Education and training of disability staff in how to deliver positive behaviour supports which are responsive to the individual and that minimise the use of restrictive practices. The NDIS Commission should consider the circumstances in which this training be mandated and the adequate provision of education and training should be reflected in the NDIS pricing arrangements.

Recommendation 11:
Implement a nationally consistent supported decision-making framework, as recommended by the Australian Law Reform Commission in their report, *Equality, Capacity and Disability in Commonwealth Laws.*

Recommendation 12:
Supported decision-making – Education and training of disability staff to ensure that people with disability enjoy legal capacity on an equal basis with others and receive the support they require in decision-making. The NDIS Commission should consider the circumstances in which this training be mandated and the adequate provision of education and training should be reflected in the NDIS pricing arrangements.

Recommendation 13:
End of life care – Education and training of disability staff in how to support people with disability to learn about death and dying, and to make choices about their participation in advance care planning. The NDIS Commission should consider the circumstances in which this training be mandated and the adequate provision of education and training should be reflected in the NDIS pricing arrangements.

Recommendation 14:
Health promotion and prevention – Education and training for disability staff in the prevention of key health risks to persons with disability, including reducing deaths related to respiratory issues and choking, epilepsy and inadequate bowel management. The NDIS Commission should consider the circumstances in which this training be mandated and the adequate provision of education and training should be reflected in the NDIS pricing arrangements.

Recommendation 15:
Build the capacity of people with disability to understand their human rights and encourage them to make complaints and actively contribute to the quality of supports they receive. A well-resourced outward facing capacity development team that promotes human rights and develops a positive complaints culture has been integral to building the knowledge and capacity of people with disability in Victoria to engage with complaints mechanisms.

Recommendation 16:
Increase publicly available information and education for people with disability and their natural support networks about the operation of quality, safeguarding and oversight mechanisms under the NDIS Quality and Safeguards Framework, including arrangements in place for registered and unregistered providers.

Recommendation 17:
Strengthen working definitions of, and provide education about, the categories of reportable incidents in the NDIS Incident Management Rules, to reduce service provider discretion and under-reporting about the impact of violence, abuse, neglect and exploitation on an individual.

Recommendation 18:
Develop a nationally consistent arrangement for reviewing and investigating the deaths of people with disability, not only including those who are NDIS participants but also those who are not receiving NDIS funding.

Recommendation 19:
Consider how category and causes of death will be determined in cases not reported to state coroners, and the measures that can address under-reporting of deaths that are 'reportable' to state coroners; as recommended by Carmela Saloman and Julian Trollor in *A scoping review of causes and contributors to deaths of people with disability in Australia*.

Recommendation 20:
Legislative reforms should bring into effect a nationally consistent framework in relation to Community Visitor Programs as a key component of the NDIS safeguarding arrangements as recommended by the Office of Public Advocate (Vic) in the report, *"I'm too scared to come out of my room"*.

Recommendation 21:
Increase funding of independent advocacy to ensure that organisations responsible for independent advocacy for people with disability can adequately undertake their work in enhancing quality and safeguarding, including addressing intersectional discrimination.

Recommendation 22:
Develop more diverse and culturally appropriate Specialist Disability Accommodation (SDA) options to be made available to people with disability, beyond the group home model, that promote people's meaningful participation and inclusion in the community.

Recommendation 23:
Increase the funding and supply of appropriate and accessible housing, including private rental and public and social housing, for all people with disability, not only including those who are NDIS participants but also those who are not receiving NDIS funding.

Recommendation 24:
Enhance the capacity of people with disability to exercise their right to live independently in the community. Funding of individualised supports should allow for the development of independent living skills and for environmental adjustments to be made to their home of choice.

Recommendation 25:
Increase the Medicare Benefits Schedule to reflect the real cost of providing ongoing patient-centred care such as undertaking comprehensive assessments, regular follow-ups, and preventative measures; as recommended by the Royal Australian College of General Practitioners in their submission to this Royal Commission.

Recommendation 26:
Increase funding and development of education and training of health professionals in the human rights model of disability to enhance their capacity to provide quality health care and supports to people with disability. This training should be co-designed by people with disability and their representative organisations.

Recommendation 27:
Increase funding and development of connected and integrated health and disability services. This should include a national network of disability health specialists to support people with disability who have complex health conditions and co-morbidities.

Recommendation 28:
Enhance the capacity of police to respond to allegations of violence, abuse, neglect and exploitation impacting people with disability. This requires an increase in the availability of Disability Liaison Officers, and disability awareness training that focuses on ensuring reasonable adjustments for people with disability.

Recommendation 29:
Develop and implement a national action plan for inclusive education, to ensure a successful transition from parallel systems of education to one inclusive system of education, as recommended by Children and Young People with Disability Australia in their submission to this Royal Commission.

Recommendation 30:
Increase supports to enable people with disability to transition from segregated forms of engagement, such as day services or sheltered employment, into open and accessible employment, ensuring individuals receive equal remuneration for work of equal value.

Recommendation 31:
Allocate resources towards a nation-wide public education campaign, co-designed with people with disability and their representative organisations, that promotes human rights and a positive message of disability within the community. This should be complemented by adequate funding of other disability-led conferences and initiatives.

Recommendation 32:
Develop nationally consistent measures for the collection of government data that is disaggregated by groups such as First Nations people with disability, women and girls with disability, older people with disability and non-NDIS participants.

Recommendation 33:
Public reporting of data about the incidence and prevalence of violence, abuse, neglect and exploitation occurring in NDIS funded services. NDIA and NDIS Commission data should be linked with other key databases and made available for ethical research and intersectional analysis.

Recommendation 34:
Build the capacity of First Nations peoples and their community-controlled organisations to develop service models for the delivery of supports to First Nations people with disability, respecting that First Nations peoples be afforded their right to make choices and self-determine their own lives.

Recommendation 35:
Culturally responsive services – Education and training of disability staff in the provision of culturally responsive services for First Nations people with disability. This education should be designed and led by First Nations peoples. The NDIS Commission should consider the circumstances in which this training be mandated and the adequate provision of education and training should be reflected in the NDIS pricing arrangements.

Recommendation 36:
Gendered disability violence – Education and training of disability staff about forms of gendered disability violence, abuse, neglect and exploitation experienced by women and girls with disability. The NDIS Commission should consider the circumstances in which this training be mandated and the adequate provision of education and training should be reflected in the NDIS pricing arrangements.

Recommendation 37:
Contingency funding for practical supports and accommodation to be immediately accessible to people with disability who experience crises as a result of their experience of violence, abuse, neglect and exploitation.

Recommendation 38:
Older people with disability – Education and training of disability staff in how to support the complex health needs of people with disability as they develop age-related health conditions. The NDIS Commission should consider the circumstances in which this training be and the adequate provision of education and training should be reflected in the NDIS pricing arrangements.

Recommendation 39:

Funding to be directed to community organisations to implement Circles of Support and the Microboard model of support. This should allow for education and training of people with disability, supporters and service providers about principles of supported decision-making.

Recommendation 40:

Human rights approach – Education and training of staff in the human rights model of disability. This training should be co-designed by people with disability and their representative organisations. The NDIS Commission should consider the circumstances in which this training be mandated and the adequate provision of education and training should be reflected in the NDIS pricing arrangements.

Recommendation 41:

That consideration be given to how NDIA pricing of supports can be improved to accommodate the additional administration and professional development costs incurred by disability service providers as a result of operating in an NDIS environment.

Recommendation 42:

That the NDIS Commission consider highlighting the report by our office, *Building safe and respectful cultures* as a community of practice approach and collaborative methodology that can be used to improve organisational culture within disability services, and to identify and address early indicators of violence, abuse, neglect and exploitation.

1. The policy context

Segregated and institutional settings

Historically, much of law, policy and practice relating to disability has adopted a medical approach, which views people with disability as objects that need to be fixed.[6] In contrast, the social approach recognises that disability is not merely the result of an individual's impairment, rather disability may occur because of the way that society responds to the person in relation to an impairment, such as through discrimination and exclusion.[7]

The social approach to disability has advanced our understanding of how to achieve inclusion for people with disability by focusing on policies that seek to remove these societal barriers.[8] This includes breaking down physical and non-physical structures that segregate and institutionalise people with disability. Such segregated settings include, though are not limited to, group homes, special developmental schools, sheltered workshops and day programs.[9] Segregation removes people with disability from natural community environments and places them into relationships, generally with paid staff and others in the same situation. Where there is a lack of natural family and social networks and supports, abusive cultures can develop.

Our office has observed the harmful effects of segregation, particularly in residential settings. Deinstitutionalisation in Victoria has seen a shift from housing people with disability in large institutions to shared supported accommodation that combines housing with 24-hour staff support, usually in the form of group homes. While the NDIS Specialist Disability Accommodation Rules state that new builds are not to allow for more than five people, there are over 100 existing homes forming DHHS legacy stock that will continue to accommodate more.[10]

There are a number of factors in supported accommodation that we observe have contributed to violence, abuse, neglect and exploitation of people with disability. A key problem is the group home model itself; the service type that has triggered the largest number of in-scope enquiries and complaints to our office.[11] Group homes can often replicate institutional living arrangements. This is because rarely are people provided with opportunities to choose their service provider, which staff will be employed, and what supports will be prioritised.[12]

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6. Anna Arstein-Kerslake, *Restoring Voice to People with Cognitive Disabilities: Realising the Right to Equal Recognition before the Law* (Cambridge University Press, 2017) 70.

7. Theresia Degener, 'Disability in a Human Rights Context' (2016) 5 *Laws* 1, 3.

8. Tom Shakespeare, *Disability: The Basics* (Routledge, 2018) 14.

9. Anna Arstein-Kerslake, *Restoring Voice to People with Cognitive Disabilities: Realising the Right to Equal Recognition before the Law* (Cambridge University Press, 2017) 195.

10. Office of the Public Advocate, *"I'm too scared to come out of my room": Preventing and responding to violence and abuse between co-residents in group homes* (November 2019) 27.

11. Disability Services Commissioner, *2018-19 Annual Report* (2019) 12.

12. Sally Robinson and Lesley Chenoweth, 'Preventing abuse in accommodation services: From procedural response to protective cultures' (2011) 15(1) *Journal of Intellectual Disabilities* 63, 66.

In group homes, people with disability commonly have their everyday routines and structures determined by managers and staff.[13] Staff may make decisions about daily meal choices, for example what food is purchased and when it can be eaten; scheduling of activities of daily living such as bathing and sleeping; social interactions, including who is allowed to enter a home or if there is a curfew; and the kinds of leisure activities and community outings available. In addition, these routines and structures are often designed for the group rather than the individual.

While any form of accommodation – from large institutions to small and large group homes, or private dwellings – may present as institutional in nature,[14] we are concerned that Australia has relied upon the group home as the primary housing model for people with disability. Splitting large institutions into smaller ones with the aim of reducing the number of persons living in a dwelling, only results in the replacement of one type of institution with another.[15] We discuss issues pertaining to homes and living in further detail throughout this submission and specifically in section 4.

> **Recommendation 1:**
> **A national framework for the closure of disability-specific residential institutions, including group homes, that do not meet the requirements of the Convention on the Rights of Persons with Disabilities or that do not comply with all domestic laws that apply, including those in relation to the *National Disability Insurance Scheme (NDIS) Act*.**

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13. Anna Arstein-Kerslake, *Restoring Voice to People with Cognitive Disabilities: Realising the Right to Equal Recognition before the Law* (Cambridge University Press, 2017) 196.
14. Human Rights Council, *Thematic study on the right of persons with disabilities to live independently and be included in the community: Report of the United Nations High Commissioner for Human Rights*, UN Doc A/HRC/28/37 (12 December 2014) [21].
15. Ibid [22].

A human rights-based approach

The disability rights movement, and linked social movements away from institutional approaches, provided momentum for the drafting of the *Convention on the Rights of Persons with Disabilities* (the Convention).[16] The Convention offers a human rights-based alternative for service provision, placing people with disability at the centre of their own lives, and as subjects of rights.[17] The drafting of the Convention was ground-breaking in terms of the principal participation of people with disability and their representatives, in keeping with their slogan 'nothing about us without us'.

While the Australian Government has signed and ratified the Convention and its Optional Protocol,[18] and argues strongly for the advancement of human rights set forth in the Convention, it has demonstrated a disinclination to fully commit domestically. The Australian Government does not offer a constitutional guarantee for human rights or a written catalogue of human rights protections.

This lack of domestic human rights law perpetuates inconsistencies and gaps across Australian states and territories, and it impacts substantially upon people with disability who historically have been marginalised within the community. Our office is acutely aware of injustices and the indignities impacting upon people with disability, through the information we receive about their lived experience of violence, abuse, neglect and exploitation.

In Victoria, human rights are recognised and protected in law through a dedicated charter of human rights. The *Charter of Human Rights and Responsibilities Act 2006* (Vic) (the Charter) compels my office, as a public authority, to adopt a human rights framework when engaging in analysis of issues impacting people with disability. This Charter is critical to the work of our office, given we encounter human rights subject matter in virtually all the office's activities and decision-making.

However, the full potential of the Charter has been limited because of the way in which section four of the Charter defines a public authority. The Charter applies to disability service providers within the sector that are or function as public authorities. We have found that a lack of clarity around this definition has led non-government disability service providers to assume they are not public authorities, when in fact they maintain a responsibility to uphold Charter rights when they are providing a service that is public in nature. In Victoria, it also remains unclear whether NDIS providers will be covered by the Charter.[19]

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16. *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008).
17. Committee on the Rights of Persons with Disabilities, *General Comment No 5 (2017) on living independently and being included in the community*, UN Doc CRPD/C/GC/5 (27 October 2017) [5].
18. United Nations, *Status of Treaties*: Convention on the Rights of Persons with Disabilities (8 July 2019) United Nations Treaty Collection https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en; United Nations, *Status of Treaties*: Optional Protocol to the Convention on the Rights of Persons with Disabilities (8 July 2019).
19. Australian Human Rights Commission, *A future without violence: Quality, safeguarding and oversight to prevent and address violence against people with disability in institutional settings* (June 2018) 48.

Further, where the Charter is accepted as applying to a provider, we do not always see it upheld in practice. For example, we regularly find that service providers develop policies and procedures that comply with the Charter, however we observe that those policies and procedures are not being routinely followed or enforced. It is our view that governments should fully incorporate human rights legal protections into domestic law, and that the legal safeguards embedded in the Charter not be diminished with the transition to the NDIS.

> **Recommendation 2:**
>
> The full incorporation of the *Convention on the Rights of Persons with Disabilities* into domestic law, including through the development of a national Human Rights Act.

> **Recommendation 3:**
>
> Strengthening of human rights legislation in relation to the responsibilities of public authorities. In Victoria, this should include clarification and education around who is a public authority under the *Victorian Charter of Human Rights and Responsibilities.*

Disability inclusive policy

In Australia and elsewhere, people with disability experience marked inequalities and are more likely to experience poverty and other forms of social exclusion than the general population.[20] People with disability are less likely to be employed, find suitable housing, receive an education, or access justice.[21] They may be restricted in their participation in political and cultural life, in sport and recreation, and in social connections and community groups.

The National Disability Strategy 2010-2020 (the 'Strategy')[22] is Australia's overarching policy framework for disability reform and the key mechanism for driving disability inclusive policy and program design in alignment with the principles of the Convention. While states and territories have their own disability strategies, this was the first time in Australia that all governments signed and committed to a national strategy with long-term goals.

The Strategy aims to overcome the siloing of disability policy within disability-specific areas within governments, by increasing the responsiveness of policies in areas of health, education, employment, housing and income support.[23] While the principles and policy areas of the Strategy are a good response to Australia's obligations under the Convention, the Strategy has not been implemented through a systematic approach across Australia.[24]

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20. Commonwealth of Australia, *National Disability Strategy 2010-2020* (2001) 12.
21. Catalina Devandas Aguilar, *Report of the Special Rapporteur on the rights of persons with disabilities*, UN Doc A/HRC/71/314 (9 August 2016) [6].
22. Commonwealth of Australia, *National Disability Strategy 2010-2020* (2001).
23. Committee on the Rights of Persons with Disabilities, *Combined second and third periodic reports submitted by Australia under article 35 of the Convention*, UN Doc CRPD/C/AUS/2-3 (5 February 2019) [17, 33].
24. Social Policy Research Centre, *Review of implementation of the National Disability Strategy 2010-2020: Final Report* (2018) 1.

The Australian Government, at the time of writing, is engaged in the development of a new 10-year National Disability Strategy for beyond 2020. We endorse the revision of this Strategy, and view that its implementation should be strengthened through central leadership, better coordination and the introduction of specific targets to raise the new Strategy's profile across all government departments and agencies. This could be directed by an Office of Disability, within a central agency, such as the Department of Prime Minister and Cabinet.

Linked national disability plans across policy areas, including health, housing, education and justice, are also important if the new Strategy is to gain traction. The new Strategy should also mandate that government agencies and disability service providers that function as public authorities, complete action plans on the steps they plan to take in the key policy areas. It should also embed stronger accountability mechanisms through public reporting on the progress of the new Strategy.

Critically, the Australian Government must consult and actively involve people with disability in all aspects of the new Strategy. This is because people with disability know best which barriers they face in the context of their everyday lives.[25] The effectiveness of a new Strategy will be shaped by the extent to which the government establishes permanent consultation mechanisms for the active engagement of people with disability and their representative organisations in its development, implementation and evaluation.

Recommendation 4:
Develop and establish a new ten-year National Disability Strategy, directed by an Office of Disability within a central agency such as the Department of Prime Minister and Cabinet, to monitor progress and oversee implementation of the new Strategy.

Recommendation 5:
That the new National Disability Strategy incorporates clear, measurable goals and timelines for implementation of those goals; mandatory action plans for all levels of government and disability service providers; regular public reporting processes; and additional resources to achieve desired outcomes.

Recommendation 6:
Establish permanent consultation mechanisms for the active engagement of people with disability and their representative organisations in the development, implementation and review of the new National Disability Strategy and disability inclusive policies.

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25. Catalina Devandas Aguilar, *Report of the Special Rapporteur on the rights of persons with disabilities,* UN Doc A/HRC/71/314 (9 August 2016) [63].

2. Preventing and protecting people with disability from experiencing violence, abuse, neglect and exploitation

> **Terms of reference (a)**
>
> **What governments, institutions and the community should do to prevent, and better protect, people with disability from experiencing violence, abuse, neglect and exploitation, having regard to the extent of violence, abuse, neglect and exploitation experienced by people with disability in all settings and contexts.**

Person-centred practice

Person-centred planning is an individualised approach to organising support for people with disability, with the view to considering and developing an individual's capabilities and strengths, rather than focusing on their deficiencies.[26] It is underpinned by the idea that activities and relationships are an important way in which quality of life is achieved.[27] Thus, it promotes and emphasises planning for supports that are flexible and adaptable to achieving the person's goals in these areas.

Aside from a recent improvement in person-centred planning undertaken for the purposes of NDIS planning, our office has observed significant shortcomings in the quality of plans created for individuals by disability service providers. For example, individualised plans are commonly incomplete, planning meetings do not always involve the individual or their natural support network, and goals are not written in specific measurable terms or reviewed within clearly defined timelines.

We have found that even when person-centred planning is of high quality, service providers fail to enact individualised plans in everyday practice. This implementation gap is evident in how disability support workers may prioritise doing household work over other activities that might be meaningful to the individual, such as spending time outdoors. Or staff might assist people with ordinary activities, such as eating meals and dressing, however with low levels of engagement, for example, without asking what that person might want to eat or wear.

In research contracted by our office, we found it is attention to the 'little things' and the relationships between staff and people with disability that impacts significantly upon the quality of care and the sense of safety that people with disability experience. For example, when staff and people with disability chat warmly while setting the table together, or when encouragement is provided by a support worker to an individual while eating, it can positively affect quality of life.[28]

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26. Victoria Ratti et al, 'The effectiveness of person-centred planning for people with intellectual disabilities: A systematic review (2016) 57 *Research in Developmental Disabilities* 64, 64.

27. Christine Bigby et al, 'Quality of practice in supported accommodation services for people with intellectual disabilities: What matters at the organisational level' (2020) *Journal of Intellectual & Developmental Disability* (advance) 1.

28. Sally Robinson et al, *Building safe and respectful cultures in disability services for people with disability* (Report for the Disability Services Commissioner, June 2019) 94

An approach of Active Support can mitigate against disengagement, by tailoring support to ensure that people with disability are provided with just the right amount of assistance to experience success during participation.[29] We are aware of an online learning resource 'Every moment has potential', which was developed to assist disability staff to enact this approach.[30]

Disability support workers should also be provided with opportunities for practical, hands-on training in Active Support. This is because research has shown that the implementation of Active Support is more effective if senior leaders of an organisation exercise practice leadership close to frontline service delivery, with coherence in their enactment of person-centred values and actions.[31]

> **Recommendation 7:**
> **Person-centred practice – Education and training of disability staff in person-centred planning and the implementation of Active Support. The NDIS Commission should consider the circumstances in which this training be mandated and the adequate provision of education and training should be reflected in the NDIS pricing arrangements.**

Communication supports

Critically, the right to freedom of expression and opinion is considered to encompass both the right to communicate (to share ideas and information with others), and as is implied by this, the right *to be able* to communicate (to have a mode of communication).[32] By enabling people with disability to communicate on an equal basis with others and through a form of communication of their choice, human rights can be secured in other spheres of life, including in health, education and employment.

Regretfully, our office has observed how people with disability, who have high communication support needs, are limited in their access to ongoing speech pathology. In 2018-2019, we found multiple instances when reviewing the death of a person with disability who had no verbal communication, that they had never had a communication assessment by a speech pathologist, despite having lived in group homes for most of their lives. It is fundamentally unacceptable that people could have received disability supports for so long without a formal communication assessment to facilitate their ability to communicate with, and be understood by, their family and social network, support workers and other people in the community.

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29. Christine Bigby, Emma Bould & Julie Beadle-Brown, 'Implementation of active support over time in Australia' (2019) 44(2) *Journal of Intellectual & Developmental Disability* 161, 161.
30. Department of Industry (Cth) (2015) *Every moment has potential* (Web Page) <http://www.activesupportresource.net.au/>.
31. Christine Bigby et al, 'Quality of practice in supported accommodation services for people with intellectual disabilities: What matters at the organisational level' (2020) *Journal of Intellectual & Developmental Disability* (advance) 11.
32. Jane McCormack, Elise Baker & Kathryn Crowe 'The human right to communicate and our need to listen: Learning from people with a history of childhood communication disorder' (2018) 20 *International Journal of Speech-Language Pathology* 142, 142.

Critically, the risk of poor health outcomes and premature death increases if a person with complex communication needs is not assessed and supported to express their needs effectively.[33] In these situations, support workers must be familiar and even more alert to the signs of illness or pain, indicators of which may include behavioural changes, such as refusing to eat or drink.

A failure to engage a speech pathologist means that people do not access the full benefits of individualised communication aids and technologies that they may require, including augmentative and alternative communication. Significantly, it places people at increased risk of violence, abuse, neglect and exploitation. Women with cognitive disability or complex communication impairments are significantly more at risk of sexual assault if they experience difficulties in communicating what has happened.[34]

Further, it is essential that all Australians, whatever their communication skills or type of disability, be supported to participate and be included in the community. This requires resourcing and mainstreaming of accessible formats of communication in government messaging, including plain-language formatting, captioning, sign language interpretation and Braille.

Recommendation 8:

Communication supports – Education and training of disability staff to ensure people who require communication supports are assessed annually by a speech pathologist and have a detailed communication plan implemented. The NDIS Commission should consider the circumstances in which this training be mandated and the adequate provision of education and training should be reflected in the NDIS pricing arrangements.

Recommendation 9:

All governments should provide all information in accessible formats, including plain-English formatting, captioning, Australian Sign Language (Auslan) and Braille.

33. Disability Services Commissioner, *A review of disability service provision to people who have died 2018-2019* (2019) 10.
34. Jane Maree Maher, et al *Women, disability and violence: Barriers to accessing justice – Final Report* (Australia's National Research Organisation for Women's Safety, April 2018) 27.

Positive behaviour supports

Restrictive practices involve the use of interventions and practices that have the effect of restricting the rights or freedom of movement of a person with disability.[35] Typically, these practices are used with people with disability who display 'challenging behaviours' or experience behaviours of concern. These practices, when unauthorised, infringe upon people's human rights, and can have a serious impact on an individual's health and wellbeing.

Our office has completed multiple investigations which found restraints were not being administered in accordance with an approved Behaviour Support Plan, including a failure to apply least restrictive principles, or to consult with families. We have also uncovered unauthorised restrictive practices, such as mechanical restraint including restrictive clothing; chemical restraint through the use of psychotropic medication; and isolation or seclusion, such as the locking of bedrooms.

In a 2018-2019 investigation, we found that staff at a group home used unauthorised restrictive practices with a man with intellectual disability who was nonverbal in his communication, prior to his death from pneumonia. To reduce the impact of loud vocalisations, this person's bedroom was sound-proofed, a second set of doors were installed in the corridor, and staff wore noise cancelling earmuffs. It is not uncommon for such actions to be justified on the grounds of protecting the rights and safety of staff, without a deep consideration of less restrictive alternatives that respect the rights of people with disability.[36]

Restrictive practices may be influenced by diagnostic overshadowing, for example, where behavioural problems are attributed to a disability at the outset, without any attempt to understand if there are other underlying causes of the behaviour. In another 2018-2019 investigation, support workers did not identify that severe constipation was a possible cause of distress to a person who was non-verbal in their communication but who was vocalising loudly. Rather than investigating further, the support workers wore noise cancelling earmuffs to block this nonverbal expression of distress. Further, staff did not recognise that their actions constituted a dehumanising form of restrictive practice.

The Positive Behaviour Support Model is an evidence-based therapeutic approach for the support of a person presenting with behaviours of concern, which can help to reduce or eliminate the use of restrictive practices.[37] Positive behaviour support should be provided through proactive measures that enhance quality of life generally, rather than applied in response to a crisis point.[38]

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35. Jeffrey Chan 'Challenges to realising the Convention on the Rights of Persons with Disabilities (CRPD) in Australia for people with intellectual disability and behaviours of concern' (2016) 23(2) *Psychiatry, Psychology and Law* 207, 210.
36. Ibid.
37. Ibid 211.
38. Office of the Public Advocate, *"I'm too scared to come out of my room": Preventing and responding to violence and abuse between co-residents in group homes* (November 2019) 42.

The NDIS Commission is involved in the development of a regulatory framework and nationally consistent minimum standards in relation to the use of restrictive practices.[39] It has also produced resources to educate specialist behaviour support practitioners and registered providers to adhere to the NDIS Restrictive Practices and Behaviour Support Rules.[40] Our findings highlight that to combat poor practices that may be entrenched in an organisation, it is important that staff receive practical training in how to deliver quality positive behaviour supports.

> **Recommendation 10:**
> **Positive behaviour supports - Education and training of disability staff in how to deliver positive behaviour supports which are responsive to the individual and that minimise the use of restrictive practices. The NDIS Commission should consider the circumstances in which this training be mandated and the adequate provision of education and training should be reflected in the NDIS pricing arrangements.**

Supported decision-making

People with disability may want or require support to make decisions. The supported decision-making model set out in the Australian Law Reform Commission's report, *Equality, Capacity and Disability in Commonwealth Laws* seeks to ensure that people with disability receive the support necessary to make, communicate and participate in decisions that affect them.[41] Further, under this model supporters have a duty to ensure the will and preferences of the individual direct decisions that are made; in contrast to substitute decision-making with its emphasis on outside judgments about what is in an individual's best interests.'[42]

When barriers to decision-making arise, people may be forced to exert their legal agency where they otherwise should not need to, for example, about their daily routine, personal relationships, clothing, nutrition, and so on.[43] While some people with disability may feel confident to speak up, others who are consistently denied the opportunity to make decisions through participation in daily activities, may not develop or maintain the skills necessary to make those decisions.[44]

39. Graeme Head (11 February 2020) *Witness Statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* [155].
40. *NDIS (Restrictive Practices and Behaviour Support) Rules 2018*.
41. Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* (Commonwealth of Australia, August 2014) 67.
42. Ibid 116.
43. Anna Arstein-Kerslake, Restoring *Voice to People with Cognitive Disabilities: Realising the Right to Equal Recognition before the Law* (Cambridge University Press, 2017) 153.
44. Ibid 196-197.

In research contracted by our office, we found people with disability may be nervous or hesitant to raise issues because support workers sometimes were too rushed to listen, or not perceived to be in a good mood and people were concerned about further upsetting them.[45] In addition, on some occasions, when people with disability raised problems they had no recollection of receiving feedback about the outcome, or it was considered that no changes or no meaningful change occurred.[46]

Families too who believe in and encourage supported decision-making, can find it difficult to know how to support the decision-making of their family member. For example, we have found that families may be reticent to speak up about a problem, because they are aware that they do not have a full understanding of the situation or they are worried that by raising minor concerns or small indignities, their family member will be impacted by a disproportionate response.[47]

While the shift to supported decision-making can empower people with disability, it may be less straightforward to implement in practice. It is not uncommon for families to occupy a position more in keeping with substitute decision-making, having more reliance on the service to take responsibility for providing support to their family member when making decisions, as well as lower expectations of their family member's capabilities and agency in decision-making.[48]

The differing values and approaches that can be taken in relation to supported decision-making may create tension or conflict among people with disability, their families, and support workers.[49] We consider that dedicated resources are required to embed supported decision-making in the everyday practices of the disability sector; training should assist people with disability, their families and disability support workers to understand core principles of supported decision-making, and how to engage in collaborative working practices. We discuss this issue further in Section 6 in relation to organisational culture.

45. Sally Robinson et al, *Building safe and respectful cultures in disability services for people with disability* (Report for the Disability Services Commissioner, June 2019) 77.
46. Roger Stancliffe et al 'Knowing, planning for and fearing death: Do adults with intellectual disability and disability staff differ?' (2016) 49-50 *Research in Developmental Disabilities* 47, 56.
47. Sally Robinson et al, *Building safe and respectful cultures in disability services for people with disability* (Report for the Disability Services Commissioner, June 2019) 92.
48. Ibid 61.
49. Christine Bigby, Mary Whiteside & Jacinta Douglas 'Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services' (2019) 44(4) *Journal of Intellectual & Developmental Disability*, 396, 406.

Recommendation 11:

Implement a nationally consistent supported decision-making framework, as recommended by the Australian Law Reform Commission in their report, *Equality, Capacity and Disability in Commonwealth Laws*.

Recommendation 12:

Supported decision-making – Education and training of disability staff to ensure that people with disability enjoy legal capacity on an equal basis with others and receive the support they require in decision-making. The NDIS Commission should consider the circumstances in which this training be mandated and the adequate provision of education and training should be reflected in the NDIS pricing arrangements.

End of life care

At the core of supported decision-making is the idea that all persons, except in very limited circumstances, have some level of decision-making ability, and that with appropriate support, they can be supported to make decisions.[50] People with disability may formally appoint their supporter, including a family member, friend or carer to assist them in a range of life decisions, including in relation to medical treatment and end of life care.

A principal issue that we observe in our work, is that service providers are not always clear about how to implement supported decision-making in relation to end of life care. This is particularly the case for people with cognitive disability. In our investigations, it is evident that support workers have implemented Advance Care Directives, completed and signed by family members, despite the directive not being a suitable legal document when an individual does not have capacity to complete it.

We have also observed that advance care planning for people with disability commonly does not occur, or it is implemented as a rushed response to a person's rapidly deteriorating health. This lack of a timely and proactive approach contributes to a narrowed medical emphasis, for example, the making of resuscitation orders and directives on life-sustaining treatments. It is a missed opportunity for people to consider and express their preferences, including about where they would like to die or their spiritual needs for dying (such as wishes for visitation).[51]

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50. Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* (Commonwealth of Australia, August 2014) 99.
51. Michele Wiese et al, 'What is talked about? Community living staff experiences of talking with older people with intellectual disability about dying and death' (2014) 58(7) *Journal of Intellectual Disability Research* 679, 686.

We find that where there is an absence of formal arrangements, family members typically assume the role as supporter. However, this too can cause problems. In 2018-2019, we observed how some families were provided with the choice between actively treating or withholding treatment from an individual with cognitive disability, despite not having a close and continuing relationship with the individual. In such cases, service providers were aware of this tension, however, did not proactively request the advice or intervention of the Office of Public Advocate (OPA).

Medical professionals do not always support people with cognitive disability to exercise their right to decision-making about their medical treatment. A common example is how attempts are not always made to involve an individual in discussions about their medical treatment. We have also observed too often cases where the decision to withhold treatment or to refer to palliative care, has been made in relation to medical professional's perception of the person's quality of life rather than to best practice procedures for the person's presenting conditions and treatment options.

It is not always evident that medical professionals consider other life-prolonging treatments for people with disability; rather they may make a value judgment about what the individual should want or what is in their best interests. This practice appears to be shaped by ableist assumptions that the quality of life of people with disability is very low, and that they will never live happy and fulfilling lives. Ableism leads to discrimination, including the denial of treatment on the basis of disability.[52]

Broadly speaking, people with disability encounter death without an understanding about what may be happening, and this situation can be compounded by a fear of death.[53] It is essential that disability staff have the skill and confidence to assist people with disability to learn over their lifespan about death and dying.[54] 'Talking end of life with people with intellectual disability' is one online learning resource developed by stakeholders to assist disability support workers and managers to acquire the skills and confidence to have such conversations.[55]

We support the view of the OPA that funding should be provided to provide support to people who require support for decision-making about medical treatment, beyond the realm of NDIS planning.[56] For example, we are aware of the beneficial impact of the Decision Support Pilot, which provides independent advocacy and decision-making support to NDIS participants who have limited decision-making capacity and a lack of either informal supporters or formal decision-making arrangements in place.[57]

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52. Catalina Devandas Aguilar, *Report of the Special Rapporteur on the rights of persons with disabilities*, UN Doc A/HRC/71/314 (9 August 2016) [31].

53. Michele Wiese et al, 'What is talked about? Community living staff experiences of talking with older people with intellectual disability about dying and death' (2014) 58(7) *Journal of Intellectual Disability Research* 679, 688.

54. Ibid.

55. Department of Health (Cth), (2018) *Talking end of life with people with intellectual disability* (Web Page) <https://www.caresearch.com.au/TEL/>.

56. Office of the Public Advocate (Vic), *Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability – Health care for people with cognitive disability* (March 2020) 12.

57. Ibid.

> **Recommendation 13:**
>
> **End of life care – Education and training of disability staff in how to support people with disability to learn about death and dying, and to make choices about their participation in advance care planning. The NDIS Commission should consider the circumstances in which this training be mandated and the adequate provision of education and training should be reflected in the NDIS pricing arrangements.**

Health promotion and prevention

People with disability are at increased risk of ill-health due to the development of secondary conditions, chronic conditions associated with risk factors such as physical inactivity, unintentional injury and falls, or due to the early onset of the ageing process in their 40s and 50s.[58] Health inequalities are significant for people with intellectual and psychosocial disability who on average die more than 15 years earlier than the general population, due to neglect, poor treatment and failure to undertake routine screening, health promotion and prevention activities.[59]

A lack of access to preventative health is particularly evident in group homes, where we observe people with disability may not receive routine immunisations, screening for cancer and interventions for a range of mental health conditions. We see instances of poor oral and dental health, including where people who are missing some or all of their teeth do not see a dentist for years at a time; this compounds the risks associated with poor nutrition and swallowing issues.

It is evident that service providers do not always individualise preventative measures on offer to their residents. For example, the same general practitioner may conveniently visit all residents in a group home. In 2015, we received a complaint about five women with intellectual disability in a group home who received near identical bulk tooth extraction – one individual had 22 teeth removed. Our investigation found the service provider failed to: facilitate annual dental health care, obtain informed consent, and provide pain relief and post-operative care. This poor quality of care is unacceptable.

Low expectations of people with disability reduce their participation in preventative health initiatives, and they do not always receive support to lead healthy lifestyles, such as through a balanced diet and physical exercise. Our office has observed how many people with disability in group homes may spend a lot of time in their own rooms engaging in sedentary activities such as watching television or listening to music. In some instances, this separation is used to minimise conflict among residents, yet it can compound their social isolation.[60]

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58. World Health Organisation, *World Report on Disability* (2011) 59.
59. Catalina Devandas Aguilar, *Report of the Special Rapporteur on the rights of persons with disabilities*, UN Doc A/HRC/73/161 (16 July 2018) [22].
60. Sally Robinson et al, *Building safe and respectful cultures in disability services for people with disability* (Report for the Disability Services Commissioner, June 2019) 79.

The net effect of this lack of access to health promotion and disease prevention services, is that in Victoria, as has occurred in other states and territories, we have found that people with disability in receipt of disability services die approximately 25 to 30 years younger than the general population.[61] While people with disability may experience complex health conditions and co-morbidities that increase ill-health, it is also clear through our investigations that deaths are preventable.

Overall, the number of potentially avoidable deaths of people with disability represents a failure of disability services to manage the key health risks impacting people with disability in receipt of services. We have found specific health management plans are not consistently created, or up to date; staff may consider that this falls to the responsibility of others. This is despite known risks to an individual in areas such as choking and aspiration, chronic constipation and epilepsy.

Indeed, many of the deaths reported to our office continue to be unexpected, for example, due to aspiration pneumonia and choking on food.[62] We are concerned that these deaths occur despite it being known that a person had difficulty swallowing and eating. It appears, in such cases, the person died because staff were either unaware of, or did not follow, their mealtime support plan. Further, staff do not always recognise when a person's health is deteriorating, or they do not escalate action by calling for appropriate medical advice or emergency care.

We have found that partnership with stakeholders across the disability and health sectors to be most effective in addressing these barriers to preventative health. For example, our office has convened a working group focused on ensuring people with disability receive appropriate mealtime supports. A range of cross-sector representatives, including the NDIS Commission, have participated to effect change, including through the development of an educative poster for display in relevant disability services to alert staff to this risk.

> **Recommendation 14:**
>
> **Health promotion and prevention – Education and training for disability staff in the prevention of key health risks to persons with disability, including reducing deaths related to respiratory issues and choking, epilepsy and inadequate bowel management. The NDIS Commission should consider the circumstances in which this training be mandated and the adequate provision of education and training should be reflected in the NDIS pricing arrangements.**

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61. *Disability Services Commissioner, A review of disability service provision to people who have died 2018-2019* (2019) 7.
62. Ibid 6.

3. Reporting, investigating and responding to violence, abuse, neglect and exploitation of people with disability

> **Term of Reference (b)**
>
> **What governments, institutions and the community should do to achieve best practice to encourage reporting of, and effective investigations of and responses to, violence against, and abuse, neglect and exploitation of, people with disability, including addressing failures in, and impediments to, reporting, investigating and responding to such conduct.**

Responding to complaints

People with disability can face multiple barriers to making a complaint about their service provider. Our office has learnt that there are a number of reasons why people with disability do not complain, including fear of retribution and withdrawal of service; not being aware of their rights; previous negative experience with making a complaint; lack of communication support; and that they don't 'know' of experiences better than the service they are receiving.[63]

To address these barriers to complaints, people with disability should be provided with opportunities to develop their capabilities to raise issues and navigate complaints systems. Our office has undertaken preventative work, providing information to people with disability and their families on speaking up about violence, abuse, neglect and exploitation. For example, in 2018-2019, we developed a plain English resource 'Living in a disability group home? You have rights.'

Our 'It's OK to complain' campaign has contributed to the increased understanding within the Victorian disability sector about the development of a positive complaints culture and the beneficial role of effective complaint handling. Having an outward facing part of our office, our capacity development team, to promote this message has been integral to building the knowledge and capacity of people with disability in Victoria to engage with complaints mechanisms.

The NDIS Commission's communication and engagement strategy similarly aims to inform people with disability about their rights under the NDIS Code of Conduct and to encourage them to make complaints if they have concerns about the safety or quality of services they receive.[64] We note that the NDIS Commission has issued grants for the development of training and resources to support people with disability and service providers to engage with NDIS complaints processes.[65]

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63. Disability Services Commissioner, *Disability services complaints data (2007-2015): What have we learnt so far?* (2017) 20.
64. Graeme Head, *Witness Statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disabilit*y (11 February 2020) [121].
65. Ibid.

We are further encouraged that the NDIS Commission as part of implementing the NDIS Complaints Management and Resolution Rules will require registered service providers to have an internal complaints management and resolution system,[66] and that they have incorporated into their guidelines for complaints handling our work on the 'Four As' model.[67] This best practice approach recognises that people who make a complaint are generally seeking one or more of four outcomes: acknowledgement, answers, actions and apology.[68]

The NDIS Commission has broad powers in relation to registered service providers, and it will be able to take complaints about unregistered service providers where the complaint relates to a potential breach of the NDIS Code of Conduct. In doing so the NDIS Commission will have the option of enacting its various powers such as compliance notices, enforceable undertakings, injunctions, and banning providers from delivering services.[69] While these are all important safeguards, unregistered providers will not have to undertake worker screening checks, report critical incidents, or undergo independent quality audits against relevant disability practice standards.

We support people's right to choose their disability service provider, including an unregistered provider. However, we are concerned about the level of regulatory oversight for unregistered providers under the NDIS, given the high number of enquiries and complaints our office has received that were about unregistered service providers, including allegations of assault. It is important that people with disability are provided with access to clear, concise information about the quality, safeguarding and oversight mechanisms embedded in the NDIS Quality and Safeguarding Framework.

In Victoria, the introduction of the Victorian Disability Worker Commission (VDWC) is an attempt to promote consistency in worker conduct. The Disability Service Safeguards Code of Conduct applies to all disability workers in Victoria, regardless of whether they are funded through the NDIS or other providers.[70] This allows the VDWC to act upon concerns over the safety and quality of supports, for example, by issuing prohibition orders to ban unregistered disability workers.

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66. NDIS *(Complaints Management and Reportable Incidents) Rules 2018* s 8.
67. NDIS Quality and Safeguards Commission, *Effective Complaint Handling Guidelines for NDIS Providers* (2015) 14.
68. Disability Services Commissioner, *Everything you wanted to know about complaints ... Tips for service providers on successfully resolving complaints and seeing the opportunities for improvement* (2017) 12.
69. NDIS Quality and Safeguards Commission, *Compliance and Enforcement Policy* (V2.0, June 2019) 4.
70. *Disability Service Safeguards Act 2018* s 22.

Recommendation 15:

Build the capacity of people with disability to understand their human rights and encourage them to make complaints and actively contribute to the quality of supports they receive. A well-resourced outward facing capacity development team that promotes human rights and develops a positive complaints culture has been integral to building the knowledge and capacity of people with disability in Victoria to engage with complaints mechanisms.

Recommendation 16:

Increase publicly available information and education for people with disability and their natural support networks about the operation of quality, safeguarding and oversight mechanisms under the NDIS Quality and Safeguards Framework, including arrangements in place for registered and unregistered providers.

Responding to serious incidents

Through successive Ministerial Referrals, DSC has provided increasing levels of oversight of reportable incidents[71] since 2012. From 2017 this has included the authority to enquire into and investigate any incidents relating to abuse or neglect in the provision of services, and the provision of disability services to people who have died.

Our office's experience of the incident reporting mechanisms in Victoria is that the categorisation of reportable incidents has relied too greatly on a subjective decision by the service provider and staff about the degree to which the incident has impacted a person. For example, non-government service providers have been required to classify incidents as either 'Major Impact' or 'Non-Major Impact'. In this system non-major incidents were not reported to our office, and therefore not subject to effective oversight.

The NDIS Incident Management Rules exclude some acts from the definition of reportable incidents, and it allows for service provider discretion about reporting. In particular, unlawful physical contact is not a reportable incident where the contact with, and impact on, the person with disability is deemed to be 'negligible,'[72] for example, where the person had 'no reaction to the contact or only a minor reaction which was brief and barely noticeable.'[73]

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71. According to s14 of the *NDIS (Incident Management and Reportable Incidents) Rules 2018*, reportable incidents are incidents that happen, or are alleged to have happened, in connection with the provision of supports or services by registered NDIS providers. These incidents include the death, serious injury, abuse or neglect of a person with disability and the use of restrictive practices in particular circumstances.
72. *NDIS (Incident Management and Reportable Incidents) Rules 2018*, s 16 (2).
73. NDIS Quality and Safeguards Commission, *Reportable Incidents: Detailed Guidance for Registered NDIS Providers* (June 2019) 22.

An issue arising with this approach is that management and staff are not best placed to make what is a subjective decision about the impact of an incident. They may fail to appreciate or choose not to report, the impact of incidents on people with disability. This is particularly disadvantageous if the person impacted by the incident is not capable of communicating and raising how they feel, or if they do not react in ways that may typical of the broader community.

We have found that the subjective nature of incident reporting potentially minimises critical issues of concern in the disability sector. We have seen examples where incidents have not been reported because the impacted person did not or could not verbalise any distress. In one case, a person was hit in the face by another resident but was then assessed by a staff member as not having been adversely affected as they continued with activities at their day service. It is concerning that the service provider did not consider this to constitute abuse.

In 2018-2019, our office found incidents of physical assault or abuse including staff forcibly administering medications and rough handling of people with disability. Poor quality of care encompassed individuals being left unsupervised in vehicles in extreme heat and staff on active night shift falling asleep.

This service provider discretion has contributed to under reporting and limited our office's ability to assess the quality of supports offered to people with disability after an incident. If an incident is deemed not to be a reportable incident, it may fail to compel a service provider to implement secondary prevention measures that empower individuals to recognise and report abuse, as well as efforts to provide medical, psychological and social supports for abuse victims, and counselling for perpetrators.

> **Recommendation 17:**
> **Strengthen working definitions of, and provide education about, the categories of reportable incidents in the NDIS Incident Management Rules, to reduce service provider discretion and under-reporting about the impact of violence, abuse, neglect and exploitation on an individual.**

Investigations and death reviews

One of the powers afforded to our office in August 2017 was the authority to undertake systemic investigations, including Authorised Officer visits which are unannounced inspections of disability services. Authorised Officer visits allow us to visit people in their home to ascertain what might be occurring in that home, beyond the usual reporting mechanisms. They send a visible message about the quality, safeguarding and oversight mechanisms in place across the sector and reinforce that staff need to ensure that they are providing high quality supports at all times.

Wherever possible, we endeavour to take an educative, rather than punitive, approach in our investigations. We have seen encouraging results from this approach, with many service providers engaging positively throughout the investigation process and taking actions and improving services before our investigation concludes. This means that improvements to services are happening in a timely manner, with more immediate benefits for the safety and well-being of people with disability.

The NDIS Commission has the power to investigate complaints and reports of non-compliance with the NDIS Practice Standards, NDIS Code of Conduct and other legislative requirements, as well as own-motion investigations into any other matter relating to compliance.[74] However, it is our experience that the process of investigation is time and labour intensive and requires an appropriate allocation of resources.

The *National Disability Insurance Scheme Act 2013* (Cth) (the NDIS Act) mandates that all registered NDIS providers across Australia must notify the NDIS Commission of deaths of people that occurred, however the NDIS Commission has not yet committed to a national approach to reviewing all deaths of people with disability.[75] They have commenced taking action to reduce the identified risks, based on existing knowledge generated by our office and comparable state reviews in other jurisdictions; and incorporated into key research report, *A scoping review of causes and contributors to deaths of people with disability in Australia*.[76]

While we agree that not all deaths need to be investigated by the NDIS Commission, we consider a robust approach is required if the sector is to identify and address the full range of contributors to the deaths of people with disability. For example, most cases of unauthorised restrictive practices have been identified through our comprehensive death investigations; using this information we have required a service provider to make service improvements to protect all residents. Such investigations provide insight into practice issues that are not raised through complaints or incident reporting, due to unequal power relations that typically characterise service provider relationships.

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74. NDIS Quality and Safeguards Commission, *Compliance and Enforcement Policy* (V2.0, June 2019) 5.
75. NDIS Quality and Safeguards Commission, *Research: Causes and contributors to deaths of people with disability in Australia – NDIS Commission's response to recommendations* (Web Page). <https://www.ndiscommission.gov.au/causes-and-contributors-deaths-people-disability>.
76. Ibid.

We have found that there is a significant gap in our knowledge on the cause of death of people with disability in Victoria. This is influenced in part by limitations of the definition of a 'reportable death' under the Coroners Act 2008, which does not require deaths in group homes managed by non-government service providers to be reported to the State Coroner, unless they are unexpected. As DHHS continues to transition its supported accommodation services to the non-government sector, the number of deaths in-scope for coronial investigation will reduce significantly.

In Victoria, the under-reporting of 'reportable' deaths of people with disability in receipt of disability services to the State Coroner is also cause for concern. This may occur because hospital staff and disability service providers lack awareness of their reporting obligations in the event of an 'unexpected death'.[77] In 2018-2019 we identified that staff at a group home were confused about what to do when a resident died, and due to a delay in reporting, they failed to preserve evidence of relevance to a coronial investigation.

Recommendation 18:

Develop a nationally consistent arrangement for reviewing and investigating the deaths of people with disability, not only including those who are NDIS participants but also those who are not receiving NDIS funding.

Recommendation 19:

Consider how category and causes of death will be determined in cases not reported to state coroners, and the measures that can address under-reporting of deaths that are 'reportable' to state coroners; as recommended by Carmela Saloman and Julian Trollor in *A scoping review of causes and contributors to deaths of people with disability in Australia*.

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77. Carmela Salomon & Julian Trollor, '*A scoping review of causes and contributors to deaths of people with disability in Australia – Findings*' (Department of Developmental Disability Neuropsychiatry UNSW, 19 August 2019) 3.

Community Visitors

Segregated settings, such as group homes, can be closed environments. By this we mean a place where people with disability live (for the purpose of ensuring they receive care and services) that limits their autonomy and power to make decisions and choices regarding their day to day activities. It is our view that, whilst balancing the privacy of residents, it is necessary to shine a light on the daily practices of disability service providers which may constrain or enable human rights.

In August 2017 amendments to the Act enhanced our capacity to engage in greater collaboration and information sharing with external stakeholders such as the OPA and Community Visitors Board. Community Visitors play an important role visiting in-scope disability services to identify conditions or problems that may not have been reported elsewhere by people with disability, and their networks.[78]

Community Visitor schemes continue to operate alongside the NDIS, in accordance with the jurisdictional arrangements of states and territories. This is important; however, we consider that future reforms should seek to achieve national consistency and underscore the essential oversight role of Community Visitors to NDIS safeguarding arrangements. For example, we note that OPA recommends that in Victoria, independent monitoring should extend to NDIS funded non-SDA settings, such as boarding houses.[79]

In particular, we agree with the OPA that the NDIS Act should be amended to allow Community Visitors to cite key documents, such as NDIS plans, and to share information to the extent that it is necessary to advocate or raise concerns with relevant complaints bodies.[80] We consider this additional frontline oversight would be helpful to hold service providers to account for ensuring safety and quality of services so that people with disability are able to lead an ordinary and fulfilling life.

> **Recommendation 20:**
> **Legislative reforms should bring into effect a nationally consistent framework in relation to Community Visitor Programs as a key component of the NDIS safeguarding arrangements as recommended by the Office of Public Advocate (Vic) in the report,** ***"I'm too scared to come out of my room".***

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78. Department of Social Services (Cth), *NDIS Quality and Safeguarding Framework* (9 December 2016) 53.
79. Office of the Public Advocate, *"I'm too scared to come out of my room": Preventing and responding to violence and abuse between co-residents in group homes* (November 2019) 8.
80. Ibid 52.

Independent advocacy

In the section 'Responding to complaints', we raised the issue of how it can be difficult for people with disability to self-advocate about issues that impact their safety and quality of life. This is particularly evident in group homes, when social isolation and a lack of natural support networks can create an environment where people with disability may not be able to identify that what they are experiencing is violence, do not know their rights, and do not know how to report the violence or to seek help.[81]

Individual advocates therefore play an important role in ensuring quality and safeguarding for people with disability, not only in relation to disability-specific services but also in mainstream systems.[82] For example, there is limited access to skilled patient advocates to support people with disability in their access to the health system, despite the fact that having a patient advocate or a trained 'service navigator' who understands the needs, wants and priorities of the individual is often necessary.[83]

The role of advocacy is acknowledged in the NDIS Complaints Management and Resolution Rules that stipulate how people with disability who want to make a complaint should have their access to an independent advocate facilitated.[84] However, there may also be a confounding perception that the NDIS Commission's grants program and the NDIA's Information, Linkages and Capacity Building (ILC) framework will build the capacity of people with disability to self-advocate, thereby reducing the need for funding of advocacy functions.[85]

Our office has not observed this reduction in the demand for advocacy, rather advocacy bodies appear to lack the resources to do their work. There is also increasing anecdotal evidence that suggests many advocacy organisations in Victoria have had to place people with disability on waiting lists and close their books due to growing demand of their services. Not only has the transition to the NDIS increased demand for all forms of advocacy and required disability advocates to quickly acquire new knowledge and expertise,[86] their resources have been increasingly tied to supporting people with disability for the review of NDIA decisions in the Administrative Appeals Tribunal.

81. Australian Human Rights Commission, *A future without violence: Quality, safeguarding and oversight to prevent and address violence against people with disability in institutional settings* (June 2018) 15.
82. Australian Cross Disability Alliance, *Submission: Department of Social Services (DSS) Review of the National Disability Advocacy Program* (June 2016) 15.
83. Royal Australian College of General Practitioners, *Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability – Health care for people with cognitive disability* (April 2020) 8.
84. *NDIS (Complaints Management and Reportable Incidents) Rules 2018* s 15(4)(b).
85. Australian Human Rights Commission, *A future without violence: Quality, safeguarding and oversight to prevent and address violence against people with disability in institutional settings* (June 2018) 53.
86. Australian Cross Disability Alliance, *Submission: Department of Social Services (DSS) Review of the National Disability Advocacy Program* (June 2016) 12.

The Australian Government funds a range of advocacy services through the National Disability Advocacy Program (NDAP), and some states and territories also fund complementary advocacy programs.[87] The NDAP was reviewed in 2016-2017, however identified reforms and a new NDAP have not been implemented. Organisations representing people with disability report the competition for limited funding through NDAP.[88]

We are concerned that in addition to chronic under-funding, disability representative organisations across most state and territory jurisdictions are at risk of having their funding reduced, in turn limiting people with disability from accessing an advocate who is independent from service providers.[89] We further note a need for funding of systemic advocacy to highlight issues related to intersectional discrimination impacting particular groups of people with disability, including First Nations peoples, women and girls and people from culturally and linguistically diverse backgrounds (CALD).[90]

Recommendation 21:
Increase funding of independent advocacy to ensure that organisations responsible for independent advocacy for people with disability can adequately undertake their work in enhancing quality and safeguarding, including addressing intersectional discrimination.

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87. Department of Social Services (Cth), *NDIS Quality and Safeguarding Framework* (9 December 2016) 34.
88. Civil Society CRPD Shadow Report Working Group, *Disability Rights Now 2019: Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities (2019) in response to the list of issues prior to the submission of the combined second and third periodic reports of Australia [CRPD/C/AUS/QPR/2-3]* (July 2019) 12.
89. Australian Human Rights Commission, *A future without violence: Quality, safeguarding and oversight to prevent and address violence against people with disability in institutional settings* (June 2018) 54.
90. Ibid.

4. Promoting a more inclusive society for people with disability

Terms of Reference (c)

What should be done to promote a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation

Housing

Typically, in the current group home model, people have not been able to make decisions about where or with whom they live – rather they were offered accommodation with limited or no real choice around accepting or rejecting that accommodation. This has been exacerbated over the years where demand has far outstripped supply and vacancies have been prioritised to people who are already in crisis.

Our office has seen a number of issues, including frequent client to client assaults, that have arisen between people who are forced to live together or whom share a dependant relationship, but who are incompatible. This is a serious issue for safety in residential settings. A 2018-2019 investigation into the death of a woman with an intellectual disability found that she was the subject of 91 incident reports over a ten-year period, 42 of which related to assaults perpetrated by a co-resident. Despite multiple complaints to the service provider by the family, no meaningful steps were taken to address the issue.

The separation of housing and support under the NDIS is part of a commitment to advancing choice and diversity for people with disability, in recognition that there could be a constraint upon choice when one organisation provides both. However, there are limitations to how this can be practically achieved. In Victoria, government made the original decision about which non-government provider would be contracted for service provision at each house, and if an individual residing in a group home wants to change service provider, they would need to persuade other residents to agree.

Where issues arise in service provision, people with disability typically need to move to another group home, if they can find one, in order to change their service provider. In this regard, the Housing Hub is a useful website and knowledge platform that connects people with disability to suitable housing vacancies.[91] While the intent is to promote choice of co-residents, once a vacancy is located, Specialist Disability Accommodation (SDA) providers administer the process and existing residents are not always consulted on applications made by incoming tenants or their compatibility considered.[92]

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91. Summer Foundation, *The Housing Hub* (Web Page) <thehousinghub.org.au>.
92. Office of the Public Advocate, *"I'm too scared to come out of my room": Preventing and responding to violence and abuse between co-residents in group homes* (November 2019) 8.

We consider that group home options should incorporate design elements that provide for privacy, such as ensuites, and safe spaces for all residents in the event of resident conflict or incompatibility. The group home model could also be improved if it better reflected a share house model. In this approach people choose to be housemates. Whilst they have individual support plans, they could still combine funding and share support provision. In this scenario, because people are choosing to share, they are likely to have more common interests and compatibility.

In addition to group home and shared housing models, more diverse and individualised SDA options should be made available. Home Share, Shared Lives and KeyRing are more contemporary housing options which can be effective in the development of informal supports.[93] Models should also consider cultural issues, such as those relevant to First Nations people with disability.

It is important that all people with disability, including those not eligible for NDIS, build their capacity to live independently in their preferred locality and accommodation. This may require an individual be supported to engage in goal-setting and skill development in areas such as personal care and household tasks.[94] It also requires their participation in holistic planning for the range of products and systems that can be used to enhance an individual's control over activities in their home, including suitable smart home technologies, telemonitoring, and home modifications.[95]

A lack of social housing contributes to homelessness, especially for people with cognitive impairments or mental illness. The private rental system is a problem area due to affordability issues, because of the discrimination people with disability experience when trying to secure a rental property, and a lack of properties that are physically accessible. Such limitations of appropriate rental vacancies, and thin markets in particular localities, preclude people with disability from their right to live in a community of their choosing.

While we have focused on issues in the group home model, other significant human rights issues include how young people with disability continue to reside in aged care settings due to a lack of appropriate housing, and the ongoing reliance on families to provide housing and supports, in an unpaid capacity.[96] In addition, the closure of residential institutions may lead to the issue of 'transinstitutionalisation', where people with disability move from, but are similarly restricted in other institutions, such as boarding houses and prisons.[97]

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93. Independent Advisory Council to the NDIS, *Pathway to contemporary options of housing and support* (May 2018) 11.

94. Independent Advisory Council to the NDIS, *Pathway to contemporary options of housing and support* (May 2018) 11.

95. Natasha Layton & Emily Steel, 'The convergence and mainstreaming of integrated home technologies for people with disability' (2019) 9(4) *Societies* 69, 72.

96. Zoe Aitken et al, 'Precariously Placed: Housing Affordability, Quality and Satisfaction of Australians with Disabilities' (2019) 34(1) *Disability and Society* 121, 123.

97. Ilan Wiesel & Christine Bigby, 'Movement on Shifting Sands: Deinstitutionalisation and People with Intellectual Disability in Australia, 1974-2014' (2015) 33(2) *Urban Policy and Research* 178, 182.

Recommendation 22:

Develop more diverse and culturally appropriate Specialist Disability Accommodation (SDA) options to be made available to people with disability, beyond the group home model, that promote people's meaningful participation and inclusion in the community.

Recommendation 23:

Increase the funding and supply of appropriate and accessible housing, including private rental and public and social housing, for all people with disability, not only including those who are NDIS participants but also those who are not receiving NDIS funding.

Recommendation 24:

Enhance the capacity of people with disability to exercise their right to live independently in the community. Funding of individualised supports should allow for the development of independent living skills and for environmental adjustments to be made to their home of choice.

Health

People with disability, throughout their life course, have unequal access to health care services and have greater unmet health care needs compared with the general population.[98] This can be particularly pronounced for people residing in regional, rural and remote areas; travelling to tertiary hospitals and rehabilitation centres for consultation can be costly and time consuming and public transport may not be accessible or able to accommodate their needs.

People with disability do not always access specialist care, which limits the identification and management of emerging and known health conditions. They may be unable to afford to see a specialist or only able to afford a bulk-billing general practitioner, who may not have the specific skills or expertise to focus on the full range of health and wellbeing concerns that require due attention. A reliance on bulk-billing and public health services can lead to lengthy wait times for people with disability.[99]

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98. World Health Organisation, *WHO Global Disability Action Plan 2014-2021* (2015) 6.
99. Royal Australian College of General Practitioners, *Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability – Health care for people with cognitive disability* (April 2020) 8.

General practitioners play an important role in coordinating the ongoing care of people with disability, yet we have identified concerning gaps. For example, we observe how the Comprehensive Health Assessment Program (CHAP)[100] tool that is prepared as part of an annual health review, is typically incomplete or lacks sufficient explanatory information to have practical utility. There are financial disincentives for general practitioners to provide long consultations,[101] and short consultation times may limit the detection of issues early.

In our work, we have found that people with disability may be compelled to see a medical practitioner based on what is convenient for the service provider. In 2018-2019, we had one particularly concerning case where on multiple occasions, two residents were reviewed by the same psychiatrist during the one appointment, with each remaining in the consulting room while the other individual was attended to. It is unacceptable that both service provider and medical professional allowed this to occur; staff efficiencies should not be prioritised over a person's human rights.

People with cognitive disability are a high-risk group. In 2018-2019 more than half of the people whose death was reported to our office had an intellectual disability and multiple, chronic health conditions.[102] We are concerned that while it is known that multi-morbidity is a strong predictor of deaths in people with intellectual disability, there remains a gap in terms of how medical professionals and disability staff are trained and therefore confident in models of complex support.[103]

Due to their chronic health conditions, people with disability may be exposed to polypharmacy, where multiple medications are taken, thereby increasing health risks due to reactions and interactions of the medication. In 2018-2019, a woman with an intellectual disability who died due to choking had recently received an increase in the dosage of her antipsychotic medication; no behaviour charts were provided to the general practitioner to evidence the need for this change, which likely exacerbated her pre-existing swallowing difficulties.

In hospital settings, health and disability staff do not always work effectively together. Our investigations have identified that disability specific support is not consistently provided to people with disability in hospital, even when an individual lacks other existing natural social networks or would benefit from a degree of staff familiarity. In 2018-2019, one individual who lacked existing natural supports was not visited by anyone over a ten-day period, despite hospital staff informing the service provider that the person had expressed feeling isolated.

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100. *Comprehensive Health Assessment Program* available at <https://www.communities.qld.gov.au/disability-connect-queensland/service-providers/comprehensive-health-assessment-program-chap>.

101. Royal Australian College of General Practitioners, *Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability – Health care for people with cognitive disability* (April 2020) 9.

102. Disability Services Commissioner, *A review of disability service provision to people who have died 2018-19* (2019) 6.

103. Nathan Wilson et al, 'Complex support needs profile of an adult cohort with intellectual disability transitioning from state-based service provision to NDIS-funded residential support' (2020) *Journal of Intellectual & Developmental Disability* (advance) 2.

Our investigations have found disability support workers do not consistently raise the specifics of an individual's support needs or provide adequate written health summaries for hospital staff. On other occasions, disability support workers have been present, however they may not be listened to or have directly been asked by hospital staff to reduce their involvement. A positive development is how the information contained in Health Passports[104] has been used in limited circumstances, to prompt discussion and cross-sector collaboration.

The lack of a defined pathway for people with disability in hospital is also evident in the lack of reasonable adjustments made for people with disability, such as dedicated sensory spaces, additional mealtime supports, extended time for consultation or decision-making, single rooms, and accommodation for family to stay overnight. This is problematic in, for example, a hospital setting, given the fast-paced and crowded environment, which can already be over-stimulating or unfamiliar for some people with disability.

A number of factors are problematic in the discharge planning of people with disability, including inappropriate and early discharge, a lack of discharge information and education, and fewer options for multidisciplinary rehabilitation. Our investigations highlight that this may occur in part, because hospital staff incorrectly assume that group homes are staffed by nurses who are qualified to, for example, provide post-operative care and administer medications. Disability staff and management may also fail to speak up about the high risks involved in a discharge.

> **Recommendation 25:**
> Increase the Medicare Benefits Schedule to reflect the real cost of providing ongoing patient-centred care such as undertaking comprehensive assessments, regular follow-ups, and preventative measures; as recommended by the Royal Australian College of General Practitioners in their submission to this Royal Commission.

> **Recommendation 26:**
> Increase funding and development of education and training of health professionals in the human rights model of disability to enhance their capacity to provide quality health care and supports to people with disability. This training should be co-designed by people with disability and their representative organisations.

> **Recommendation 27:**
> Increase funding and development of connected and integrated health and disability services. This should include a national network of disability health specialists to support people with disability who have complex health conditions and co-morbidities.

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104. West Moreton Hospital and Health Service (2016), *This is my Health Passport* <https://www.health.qld.gov.au/__data/assets/pdf_file/0032/858362/3.-Julians-Key-Health-Passport-100gsm-LHC-staple.pdf>.

Justice

Our office has observed how people with disability, when reporting to police their experience as a victim of violence and abuse do not enjoy equality before the law. On a number of occasions, people with disability have made disclosures to police, however, police may not proceed with an investigation for reasons that remain unclear to the individual. This failure to keep people with disability informed about the progress of an investigation, may perpetuate fears that their reports to police are not being taken seriously.[105]

Police decision-making to discontinue an investigation may stem from attitudes about how to regard evidence from people with disability. Police may incorrectly assume that people with cognitive disability or communication impairments are not credible or not capable of giving evidence or making legal decisions.[106] Our investigations have found that police may consult with families about whether or not to proceed with an investigation, rather than asking the individual about what they might choose to do.

We also have learnt how support, which should be tailored to the cognitive and communication needs of the individual, is not consistently offered by police to people with disability throughout the phases of investigation. For example, people with disability may be interviewed without a support person present or without access to an Independent Third Person, this may be because it is assumed that the individual has a greater understanding of their situation than they actually do.[107]

Therefore, it is important that police are trained and supported to make reasonable adjustments for people with disability including during the initial reporting, interviewing or taking of a statement, and in communicating about the progress and outcomes of an investigation. In Victoria, the recent roll-out in each region of a police member as a 'disability liaison officer' is an important initiative;[108] we consider that a further dedication of resources would help to ensure such disability inclusive policies are translated into justice responses to violence, abuse, neglect and exploitation of people with disability.

> **Recommendation 28:**
> **Enhance the capacity of police to respond to allegations of violence, abuse, neglect and exploitation impacting people with disability. This requires, for example, an increase in the availability of Disability Liaison Officers, and disability awareness training that focuses on ensuring reasonable adjustments for people with disability.**

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105. Department of Health and Health and Human Services (Vic), *Responding to allegations of abuse involving people with disabilities: Guidelines for disability service providers and Victoria Police* (June 2018) 35.

106. Law Reform Committee, Parliament of Victoria, *Inquiry into Access to and Interaction with the Justice System by People with an Intellectual Disability and their Families and Carers* (Parliamentary Paper No 216, March 2013) 6.

107. Ibid 104.

108. Office of the Public Advocate, *"I'm too scared to come out of my room": Preventing and responding to violence and abuse between co-residents in group homes* (November 2019) 72.

Education

The inclusion of people with disability in mainstream educational settings, so they receive good quality education, enables development of their capabilities for employment and other areas of life.[109] Inclusive forms of education at all levels – in early childhood education, schools and universities, vocational training and lifelong learning, extracurricular and social activities – can also increase familiarity between people who are able-bodied and those with disability, thereby reducing prejudice and helping to promote a more inclusive society.[110]

In our office, we particularly observe the long-term impact of a lack of educational opportunities provided to people with disability who have lived for the majority of their lives in institutional settings including group homes. We are deeply concerned that people with disability have had limited opportunities to engage in meaningful education that develop their strengths, skills and competencies necessary to enjoy participation and inclusion in the local community.

We consider that education provides the means for people with disability to participate in their community and to be safeguarded from violence, abuse, neglect and exploitation. It is our view that there will be poor outcomes for students with disabilities if an educator cannot provide the supports necessary for student learning and participation, including the creation of satisfying relationships with peers.[111]

Unfortunately, despite the evidence base and human rights imperative for inclusive education, students with disabilities continue to be excluded from mainstream education in Victoria.[112] This may occur through the explicit segregation of students with disabilities to a 'special' school or class, or their exclusion in mainstream settings, where students with disabilities are present within the setting, however they are not treated as valued members of the school community or included alongside their peers.[113]

The exclusion of people with disability from mainstream educational settings is a result of a range of barriers. These barriers to participation include funding limitations, lack of specialist supports, inadequate knowledge and training about disability among teachers, lack of time for teachers to provide an individualised approach for students with disabilities, and discriminatory attitudes.[114] When there is a lack of resources or will to implement supports for people with disability, families may be inclined to seek segregated alternatives.

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109. World Health Organisation, *World Report on Disability* (2011) 205.
110. Ibid 206.
111. World Health Organisation, *World Report on Disability* (2011) 212.
112. Victorian Equal Opportunity & Human Rights Commission, *Held back: The experiences of students with disabilities in Victorian schools – Analysis Paper* (State of Victoria, 2017) 2.
113. Australian Human Rights Commission, *A future without violence: Quality, safeguarding and oversight to prevent and address violence against people with disability in institutional settings* (June 2018) 16.
114. Victorian Equal Opportunity & Human Rights Commission, *Held back: The experiences of students with disabilities in Victorian schools - Analysis Paper* (State of Victoria, 2017) 2.

Critically, it appears more effort is required to increase the capacity of educators to make all reasonable adjustments for students with disabilities.[115] This requires education and training to address discriminatory attitudes[116] and it also requires investment to ensure that specialist supports and services – including integration aids, occupational therapists and others – are proactively used to address matters outside the educators' expertise.

> **Recommendation 29:**
> **Develop and implement a national action plan for inclusive education, to ensure a successful transition from parallel systems of education to one inclusive system of education, as recommended by Children and Young People with Disability Australia in their submission to this Royal Commission.**

Employment and economic participation

There are a range of barriers to the meaningful employment and economic participation of people with disability. Young people with disability typically have low rates of educational attainment and they may not receive the appropriate supports to prepare for a future career. For example, they may lack work readiness skills typically acquired through part time work or volunteer work or there may be limited practical assistance with early career job matching and coaching.[117]

These barriers are compounded by low expectations in the community that people with disability can contribute positively to the workplace and economy. Thus, an employers' perceptions of disability may act as a barrier to the employment of people with disability. For example, they may lack awareness about the benefits of employing people with disability or demonstrate bias in recruitment processes. Further, an employer may be uncertain about, or unwilling to support people with disability through making workplace adjustments.[118]

Our office is concerned that segregated forms of engagement and employment continue to be the default option for people with disability. Participation in day services can be a problem when the primary objective is to facilitate community and social participation, rather than skill development for future employment. Our office also notes that individuals working in Australian Disability Enterprises are not being adequately supported to transition to open forms of employment, and further, that they may be receiving rates of pay well below the minimum wage.[119]

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115. Ibid 7.
116. Ibid 4.
117. Australian Human Rights Commission, *Willing to work: National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability* (2016) 202.
118. Ibid 180.
119. Australian Human Rights Commission, *Willing to work: National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability* (2016) 213.

Lower rates of labour market participation as well as lower paying jobs generally are key pathways through which disability may lead to poverty.[120] We are concerned about the flow-on effect of this low income on other parts of an individual's life, for example, people with disability may lack affordable housing or access to transport, which again creates a cycle of unemployment or underemployment. It also perpetuates a situation where people with disability may be reliant on others, even when those relationships are not safe.

> **Recommendation 30:**
> **Increase supports to enable people with disability to transition from segregated forms of engagement, such as day services or sheltered employment, into open and accessible employment, ensuring individuals receive equal remuneration for work of equal value.**

Community awareness-raising

Deinstitutionalisation policies can inadvertently contribute to new forms of segregation and social exclusion whereby people with disability may not feel a valued part of the community, despite their presence in it.[121] For example, the research contracted by our office highlighted that people with disability may feel disrespected when they are faced with a lack of activities in their daily programs that are meaningful and build upon their strengths and interests.[122]

The provision of high-quality individualised support that promotes choice and control is therefore an important precondition for living and fully participating in the community. The emphasis is on fostering a sense of belonging for people with disability, through their interactions in and with the community, for example, with neighbours, at local clubs, and on public transport.

Individualised support is a way to ensure choice and control, however it is important that people with disability are able to access non-disability specific support services and facilities for the general population in the community, such as hospitals, schools, parks, public libraries, shops, transport, museums, and the Internet.[123] Through positive encounters with people in the community, people with disability have the opportunity to extend their social space beyond peers, families and support staff, and to step outside what may be a fixed identity as a 'person with a disability.'[124] Such encounters will also provide opportunities for the broader community to extend their societal expectations of people with disability beyond that fixed identity.

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120. World Health Organisation, *World Report on Disability* (2011) 235.
121. Ilan Wiesel, Christine Bigby & Rachel Carling-Jenkins, '"Do you think I'm stupid?" Urban encounters between people with and without intellectual disability (2013) 50 (12) *Urban Studies* 2391, 2393.
122. Sally Robinson et al, *Building safe and respectful cultures in disability services for people with disability* (Report for the Disability Services Commissioner, June 2019) 78.
123. Committee on the Rights of Persons with Disabilities, *General Comment No 5 (2017) on living independently and being included in the community*, UN Doc CRPD/C/GC/5 (27 October 2017) [32].
124. Ilan Wiesel, Christine Bigby & Rachel Carling-Jenkins, '"Do you think I'm stupid?" Urban encounters between people with and without intellectual disability (2013) 50 (12) *Urban Studies* 2391, 2403.

We consider awareness-raising is imperative to challenging stereotypes and negative attitudes towards disability and people with disability. Awareness-raising should consist of training across public authorities, the private sector, and through the media about how to address the rights, concerns, and needs of people with disability.[125] The direct involvement of people with disability in these information-sharing campaigns, for example, in hospitals and schools may also alleviate discomfort or fear about disability within the community.

Awareness-raising should combat ableism, through the proactive profiling of the capabilities and contributions of people with disability. For many years, our office has been involved in the national Victorian Advocacy League for Individuals with Disability (VALID) Having a Say Conference, where people with disability share their stories, celebrate their achievements, and obtain information about their rights. We have also participated in ArtAbility, an annual exhibition led by Action on Disability within Ethnic Communities (ADEC) that features artworks by artists who have a disability and are from CALD backgrounds.

The profiling of the talents and skills of people with disability does not frequently occur within the mainstream community, and funding is crucial for it to continue. In Victoria, we note the mixed media campaign 'Change your reactions' has encouraged Victorians to learn about and understand the impacts of community actions and reactions in relation to people with autism.[126] Our office considers a targeted nation-wide public education campaign, led by people with disability and their representative organisations, should be resourced to celebrate and develop community awareness about the lived experience of all people with disability.

Recommendation 31:

Allocate resources towards a nation-wide public education campaign, co-designed with people with disability and their representative organisations, that promotes human rights and a positive message of disability within the community. This should be complemented by adequate funding of other disability-led conferences and initiatives.

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125. Catalina Devandas Aguilar, *Report of the Special Rapporteur on the rights of persons with disabilities*, UN Doc A/HRC/71/314 (9 August 2016) [74].
126. *Autism Change Your Reactions* (Web Page) <www.changeyourreactions.com.au>

5. Intersectionality and disability

> **Term of Reference (g)**
>
> The specific experiences of violence against, and abuse, neglect and exploitation of, people with disability are multilayered and influenced by experiences associated with their age, sex, gender, gender identity, sexual orientation, intersex status, ethnic origin or race, including the particular situation of Aboriginal and Torres Strait Islander people and culturally and linguistically diverse people with disability.

Intersectional data

Intersectionality helps us to understand how different sets of identities impact on access to rights and opportunities. People with disability comprise a heterogenous group with a wide range of impairments, as well as identity markers that vary according to race, colour, sex, sexual orientation, gender identity, language, religion, national, ethnic, indigenous or social origin, age or other status.[127] This diversity results in significant variability in the situation and support needs of different groups of people with disability.[128]

Disaggregated data enables understanding about the issues that impact particular groups of people with disability. Our office has a strong history of using administrative data to understand the demographics of people with disability receiving disability services, and to inquire into the quality of service delivery. We publicly report upon this data through our annual reporting mechanisms.

However, the capacity to use data in our work to more deeply uncover intersectional issues is limited. For example, in 2018-2019 only one out of 100 of the deaths reported to the DSC were of people who had identified as being First Nations, and there were no deaths reported the year prior.[129] This low number of deaths impacting First Nations peoples in our data may reflect the low rate at which First Nations people with disability access mainstream disability services, however this is an area that is not well understood, given data collection relating to First Nations people with disability is particularly limited.[130]

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127. *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515UNTS 3 (entered into force 3 May 2008) Preamble (p).
128. Catalina Devandas Aguilar, *Report of the Special Rapporteur on the rights of persons with disabilities*, UN Doc A/HRC/34/58 (20 December 2016) [42].
129. Disability Services Commissioner, *A review of disability service provision to people who have died 2018-19* (2019) 7.
130. Australian Human Rights Commission, *A future without violence: Quality, safeguarding and oversight to prevent and address violence against people with disability in institutional settings* (June 2018) 16.

We are further concerned that the mortality data for people with disability is not comprehensively recorded or integrated in a consistent way across the different Australian jurisdictions.[131] A net effect is that the mortality data across states and territories has not yet been aggregated to provide national insights or to allow state-based comparisons and understanding about what is working in relation to the wide range of support services and models of disability care.

The establishment of the NDIS provides a critical opportunity to implement nationally consistent measures for the collection and integration of disaggregated data specifically focused on the violence, abuse, neglect and exploitation occurring in NDIS funded services. Where data from the NDIS is collected and combined with other data sets, it has potential to ensure continuous policy and system improvement, if it also takes into account data about people with disability who are not NDIS participants.

Good quality data and research on disability is essential for providing effective policy and programs.[132] If data is to improve the lives of people with disability, it is important that there are effective mechanisms by which disaggregated data can be made publicly available for ethical research. Our office is aware of a national coalition of academics and stakeholders who are better positioned to learn from and analyse disaggregated data derived from practice.[133]

Recommendation 32:
Develop nationally consistent measures for the collection of government data that is disaggregated by groups such as First Nations people with disability, women and girls with disability, older people with disability and non-NDIS participants.

Recommendation 33:
Public reporting of data about the incidence and prevalence of violence, abuse, neglect and exploitation occurring in NDIS funded services. NDIA and NDIS Commission data should be linked with other key databases and made available for ethical research and intersectional analysis.

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131. Carmela Salomon & Julian Trollor, *'A scoping review of causes and contributors to deaths of people with disability in Australia – Findings'* (Department of Developmental Disability Neuropsychiatry UNSW, 19 August 2019) 5.
132. World Health Organisation, *WHO Global Disability Action Plan 2014-2021* (2015) 22.
133. Melbourne Disability Institute, *Democratising disability data collection mission statement* (Web Page) <https://disability.unimelb.edu.au/research/democratising-disability-data>.

First Nations people with disability

First Nations peoples may experience multiple layers of disadvantage and health disparities, influenced by their experience of discrimination and institutionalisation that limit their opportunities and life outcomes.[134] For example, First Nations people with disability as a group experience low levels of educational attainment, low employment and poor health outcomes.[135] This can occur because they are discriminated against due to multiple aspects of their identity, for being an Indigenous person *and* a person with a disability.[136]

As discussed in relation to the low representation of First Nations people in our data, our experience is that the kinds of disability-specific supports available, including group homes, may be different to what is wanted and accessed by First Nations people with disability. Models of care do not typically reflect whole-of-family and community models that may be suited to First Nations people with disability and their families.[137] Current models may fail to be flexible or to provide practical help such as home modifications, flexible respite and community transport.[138]

While improvements to the delivery of mainstream and disability services is important, government action should prioritise the development of culturally appropriate service models, respecting that First Nations peoples be afforded their right to make choices and self-determine their own lives. This requires direct consultation with First Nations peoples, as well as partnering with First Nations staff to elicit their insights about issues in the provision of existing services within the community.[139]

To increase First Nations peoples' access to services for people with disability, there should be additional resources allocated to support First Nations people who are willing and interested to undertake training and certification in disability work, and to progress to professional and senior positions.[140] Employing First Nations peoples is an effective way that mainstream disability services can signal their commitment to inclusion of First Nations people with disability.[141]

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134. Department of Social Services (Cth), *Australian Government plan to improve outcomes for Aboriginal and Torres Strait Islander people with disability* (2017) 10.
135. Ibid.
136. First Peoples Disability Network, I*ntersectional Dimensions on the Right to Health for Indigenous Peoples – A Disability Perspective,* (February 2016) 2.
137. Department of Social Services (Cth), *Australian Government plan to improve outcomes for Aboriginal and Torres Strait Islander people with disability* (2017) 10.
138. NSW Ombudsman, *Improving service delivery to Aboriginal people with disability* (2010) 20.
139. Ibid 7-9.
140. Ibid 12.
141. Ibid 12.

We consider that service providers should undertake critical education and training to develop their capabilities to provide culturally responsive and flexible services to First Nations people with disability. For example, the First Peoples Disability Network (FPDN) have developed the resources and workshops centered on 'Our Way Planning', that can be used by management and staff to better enable First Nations people with disability to identify the types of support they need.[142]

> **Recommendation 34:**
> Build the capacity of First Nations peoples and their community-controlled organisations to develop service models for the delivery of supports to First Nations people with disability, respecting that First Nations peoples be afforded their right to make choices and self-determine their own lives.

> **Recommendation 35:**
> Culturally responsive services – Education and training of disability staff in the provision of culturally-responsive services for First Nations people with disability. This education should be designed and led by First Nations peoples. The NDIS Commission should consider the circumstances in which this training be mandated.

Women and girls with disability

Women and girls with disability are at heightened risk of being victims of violence, abuse, neglect and exploitation in their various support arrangements compared to the general population, and their experience of violence tends to be more diverse and severe than for women in general.[143] This violence may be interpersonal in nature, or it can be institutional and/or structural and used by family members or carers to keep a woman in a subordinate position compared with other people in her family, household or community.[144]

Violence against women who live in institutional settings such as group homes is not always recognised or understood as violence.[145] This is because current legislative and policy frameworks in Australia may focus on preventing and addressing domestic and family violence that occurs within the family setting, between former or current spouses and partners.[146] While important, this framing is not representative of how violence is experienced by women and girls with disability in a range of settings that they live in and occupy.[147]

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142. First Peoples Disability Network, *Our way planning* (Web Page) <https://fpdn.org.au/our-way-planning-resources/>.
143. Catalina Devandas Aguilar, *Report of the Special Rapporteur on the rights of persons with disabilities,* UN Doc A/HRC/34/58 (20 December 2016) [43].
144. Committee on the Rights of Persons with Disabilities, *General Comment No 3 (2016) on women and girls with disabilities,* UN Doc CRPD/C/GC/3 (25 November 2016) [29].
145. Carolyn Frohmader, Leanne Dowse & Aminath Didi *Preventing violence against women and girls with disabilities: Integrating a human rights perspective* (Women with Disabilities Australia, September 2015) 15.
146. Ibid 9.
147. Ibid 14.

Our office has observed the specific impacts and normalisation of gender-based violence in group homes. For example, in 2018-2019, we received an incident report from a casual disability support worker whereby a woman had her pubic hair shaved by staff for the purported health benefit of maintaining hygiene. Our investigation found this was a routine practice endorsed by the house supervisor for all residents on the basis of staff convenience.

Issues in relation to sexual and reproductive rights impacting women are typically not disclosed to our office, however, the review of deaths provides an opportunity to learn. In one concerning 2018-2019 case, we found that a woman with an intellectual disability had her menstruation suppressed for over thirty years to prevent her perceived distress at bleeding, without the trial of other less restrictive options. This use of menstrual suppressant drugs, without seeking the consent of the individual, can be shaped by incorrect assumptions that women and girls with disability are incapable of menstrual management.[148]

Our office has found that women and girls with disability who are subject to family violence may find it difficult to report violence due to their fear that by reporting, they risk losing supports from that family member, or that they would alternatively be required to adapt to different service providers or living arrangements. This fear may be justified by funding models such as the NDIS that do not immediately wrap services around people with disability who are in crisis or emergency situations.[149]

In Victoria, we have observed the effectiveness of the Disability Family Violence Crisis Response Initiative, which provided short-term funds to secure practical supports and crisis accommodation for women and girls with disability impacted by family violence. It is imperative that resourcing allows for contingency funding to be immediately accessible when crises arise. This funding for wrap-around supports could be pre-emptively built into individual NDIS plans or made available through separate funding streams.[150]

> **Recommendation 36:**
> Gendered disability violence – Education and training of disability staff about forms of gendered disability violence, abuse, neglect and exploitation experienced by women and girls with disability. The NDIS Commission should consider the circumstances in which this training be mandated.

> **Recommendation 37:**
> Contingency funding for practical supports and accommodation to be immediately accessible to people with disability who experience crises as a result of their experience of violence, abuse, neglect and exploitation.

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148. Beth Goldblatt & Linda Steele 'Bloody unfair: Inequality related to menstruation- Considering the role of discrimination law' (2019) 41 (3) *Sydney Law Review* 293.
149. Graeme Head (11 February 2020) *Witness Statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* [188].
150. Office of the Public Advocate, *"I'm too scared to come out of my room": Preventing and responding to violence and abuse between co-residents in group homes* (November 2019) 50.

Older people with disability

People with disability experience are at greater risk of experiencing ill health than the general population, for example, they are at increased risk of developing secondary, co-morbid and age-related conditions.[151] This is shaped by issues at the intersection between disability and ageing; older people with disability are more likely to be affected by high levels of poverty, discrimination, violence and social exclusion, as well as barriers to access to health care.[152]

Despite this issue, disability support workers do not necessarily understand the changes associated with age-related conditions, such as dementia.[153] For example, we see that falls may be understood by staff as a natural part of ageing, rather than as linked to a deterioration in an individual's health. The misconception that 'nothing can be done' results in a lack of preventative action.[154]

Ageing is a barrier to physical activity for people with disability. Pessimistic beliefs about ageing can contribute to older people with intellectual disability being less physically active than younger counterparts.[155] We observe that the staffing ratios at day programs and residential settings do not allow for effective individual support to people with disability to engage in physical activity at home or in the community; activities if they occur at all tend to be group-based.

Individualised supports available through the NDIS may help to overcome barriers to the support of older people with disability, given people who start the NDIS before age 65 may choose to keep receiving services under the scheme as they age. Thus, people with disability should be able to continue to live in their group homes as they age, however this can only practically happen so long as disability support workers are confident and able to support them.[156] As mentioned, we do not typically observe this level of skills and confidence.

151. Catalina Devandas Aguilar, *Report of the Special Rapporteur on the rights of persons with disabilities*, UN Doc A/HRC/73/161 (16 July 2018) [5].

152. Catalina Devandas Aguilar, *Report of the Special Rapporteur on the rights of persons with disabilities*, UN Doc A/HRC/74/186 (17 July 2019) [8].

153. Ruth Webber, Barbara Bowers & Christine Bigby, 'Confidence of group home staff in supporting the health needs of older residents with intellectual disability' (2016) 41(2) *Journal of Intellectual & Developmental Disability* 107, 107.

154. Catalina Devandas Aguilar, *Report of the Special Rapporteur on the rights of persons with disabilities*, UN Doc A/HRC/74/186 (17 July 2019) [21].

155. Carmela Salomon et al, 'A qualitative exploration of barriers and enablers of healthy lifestyle engagement for older Australian with intellectual disabilities' (2019) 6(2) *Research and Practice in Intellectual and Developmental Disabilities* 182, 188.

156. Ruth Webber, Barbara Bowers & Christine Bigby, 'Confidence of group home staff in supporting the health needs of older residents with intellectual disability' (2016) 41(2) *Journal of Intellectual & Developmental Disability* 107, 108.

The ability of people with disability to age-in-place, if they are not eligible for NDIS or who are over age 65 and reside in group homes, is less clear.[157] A common tension occurs when people with disability are no longer able to attend day services or supported employment, because of their age, however they do not always receive the support to think about and plan for alternatives. It can also be difficult for people to access supports and funding for ageing in place given disability support workers are not routinely rostered on in group homes during the day.[158]

> **Recommendation 38:**
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> **Older people with disability – Education and training of disability staff in how to support the complex health needs of people with disability as they develop age-related health conditions. The NDIS Commission should consider the circumstances in which this training be mandated.**

157. Rafat Hussain et al, 'Perspectives about support challenges facing health workers assisting older adults with and without intellectual disability in rural versus urban settings in Australia' (2019) 44 (2) *Journal of Intellectual & Developmental Disability* 174, 175.
158. Ruth Webber, Barbara Bowers & Christine Bigby, 'Confidence of group home staff in supporting the health needs of older residents with intellectual disability' (2016) 41(2) *Journal of Intellectual & Developmental Disability* 107, 107.

6. Care and support of people with disability

> **Term of Reference (h)**
> The critical role families, carers, advocates, the workforce and others play in providing care and support to people with disability.

Strengthening natural supports

The involvement and support of family and other natural supports is integral to the long-term wellbeing of people with disability, and a critical safeguard in the provision of formal supports and services. When people with disability do not have family or other natural supports in their lives, there is the risk that they become wholly reliant on service providers, and in some cases an individual support worker, to look out for their day-to-day wellbeing and rights.

While stability and consistency in staff teams is important in enabling staff to develop a deeper understanding of individuals with whom they are working,[159] in the event of a problem an individual should have a choice of people with whom they can raise important issues.[160] This requires people with disability to build and maintain trust in a range of relationships, including with family, friends, disability staff and networks in the broader community.

In our office, we see a much lower rate of complaint investigations that have originated with people with disability; complaints are more likely to have been raised by family. Families advocate for a range of concerns, such as when their family member did not enjoy an activity, or about more complex, interpersonal issues that arise, for example conflict between people using the service.

We have referred to some of the challenges that arise for families in relation to supported decision-making and in making complaints to service providers. Families may experience a variety of stressors that can make it difficult to always support their family member who has a disability. For this reason, they too may benefit from supports, so they are not treated improperly or feel pressured to make a choice, in a range of settings such as hospitals, schools and residential settings.

In addition to individual advocacy options, a Circle of Support is a small group of family, friends, and staff or others, who actively come together to support a person, assisting them to identify what they would like to do, be and become in their lives. A Circle of Support can reduce uncertainty about an unknown future for an individual with disability, such as with ageing parents and siblings. It can help to reduce the over reliance on one particular member of a family for the majority of supports.

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159. Sally Robinson et al, *Building safe and respectful cultures in disability services for people with disability* (Report for the Disability Services Commissioner, June 2019) 106.
160. Ibid 103.

The Microboard model of support may develop or build upon an individual's Circle of Support, however, in a Microboard the group of supporters form an incorporated association with a formal legal structure that can endure across an individual's lifetime.[161] Notably, the setting up of a Microboard takes a dedication of time and resources; for example, people with disability may require support to form a group and supporters may benefit from opportunities to learn about how to implement the principles of supported decision-making.

> **Recommendation 39:**
> **Funding to be directed to community organisations to implement Circles of Support and the Microboard model of support. This should allow for education and training of people with disability, supporters and service providers about principles of supported decision-making.**

A skilled and safe disability workforce

An issue with disability services, and shared supported accommodation in particular, is the workforce, which is dispersed, increasingly casualised, often without sufficient training, and relatively lowly paid. High staff turnover brings disruption to established and valued relationships. Where a group home has a lot of different people working in it, it may become less homely.

We have observed that disability support workers may be in a state of constant busyness and stress, due to low staff-to-service user ratios. For example, they may be responsible for providing personal assistance for up to five residents at a time. Beyond this, there are no guidelines for staffing requirements for particular situations, such as when going out into the community or accessing health services, which we have found to contribute to inadequate supervision and preventable deaths of people with disability.

A lack of staffing can contribute to the violence, abuse, neglect and exploitation of people with disability. We see a high number of injuries due to unwitnessed falls, including in client bedrooms and bathrooms. This is indicative that people with disability are not always receiving the support that they require for their activities of daily living. For example, an individual may be provided with sleepover support – where help is provided if a need arises during the night – when a higher level of active night support is actually what is required.

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161. Microboards Australia (Web Page) <microboard.org.au>.

Staff who have been neglectful or abusive may be identified as lacking training and experience and have a low level of competence and experience in performing essential care tasks. Insufficient supervision and a lack of reflective practice about how to practice with people's needs and human rights in mind, are common and concerning issues. For example, in one 2018-2019 investigation we found that over a one-year duration, a service provider offered supervision to support workers only once for their performance review, and the focus of professional development was limited to hygiene and handwashing.

To be effective, staff need regular opportunities to have a supervisor watch their work and provide modelling and coaching about good practice.[162] We also consider that it should not be sufficient for disability service providers to assume that staff are providing high quality of care, rather this should be evidenced through observational data of staff practice and service user outcomes.

It is our view that a human rights approach to education can enable support workers, house supervisors and managers to be more attuned to the moral dimensions of their practice, including their ways of relating and interacting with people with disability. Indeed, the NDIS Quality and Safeguards Framework recognises such inherent tensions that characterise disability work and the balance, even in ordinary activities, of supporting each person's dignity of risk in decision-making, whilst also safeguarding against the risk of harm.[163]

The Australian Government is currently developing the NDIS Capability Framework to stipulate how NDIS Practice Standards and associated quality indicators will be translated into observable behaviours that workers should demonstrate.[164] This framework will inform the development of mandatory education and training that should apply for NDIS service delivery, for example, outlining a core capability set and a complementary set (for specialised supports and services).[165]

In this submission, we have highlighted core areas of practice that we consider should be targeted by the NDIS Commission in their work of building the capacity of NDIS service providers. These areas include person-centred care, communication supports, positive behaviour supports, supported decision-making, end of life care, health promotion and support for particular groups. We consider that the NDIS Commission should co-design training and resources with people with disability and examine closely the circumstances in which this information is mandated, such as for SDA providers.

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162. Christine Bigby et al, 'Quality of practice in supported accommodation services for people with intellectual disabilities: What matters at the organisational level' (2020) *Journal of Intellectual & Developmental Disability* (advance) 11.

163. Graeme Head (11 February 2020) *Witness Statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* [285].

164. NDIS Quality and Safeguards Commission, *NDIS Workforce Capability Framework* (Web Page, 13 April 2020) <https://www.ndiscommission.gov.au/workers/ndis-workforce-capability-framework>.

165. Department of Social Services (Cth) (2019) *Growing the NDIS Market and Workforce: Supporting the market to deliver innovative, people-centred services so that participants can achieve their goals* 9.

While the development of training and resources is critical, the extent to which the NDIS Commission can contribute to upskilling of the disability workforce may be limited by the NDIS pricing structure. Disability service providers have reported that due to inadequate funding levels, they have had to reduce training of staff or provide supervision that is infrequent, irregular, less focused on reflective practice and more task focused.[166] Not investing in quality care is counterproductive and not aligned with insurance scheme principles; it further contributes to the loss of skilled workers.[167]

We consider that the NDIA should consider how to better reflect in its pricing of supports the additional costs of professional development, and that this training should be continuous throughout all stages of a staff member's employment at an organisation. For training to remain front of mind it needs to be embedded in the organisation's culture, induction processes, at meetings, and at individual or group supervision.

> **Recommendation 40:**
> Human rights approach – Education and training of staff in the human rights model of disability. This training should be co-designed by people with disability and their representative organisations. The NDIS Commission should consider the circumstances in which this training be mandated.

> **Recommendation 41:**
> That consideration be given to how NDIA pricing of supports can be improved to accommodate the additional administration and professional development costs incurred by disability service providers as a result of operating in an NDIS environment.

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166. Sally Robinson et al, *Building safe and respectful cultures in disability services for people with disability* (Report for the Disability Services Commissioner, June 2019) 108.
167. Joint Standing Committee on the National Disability Insurance Scheme (Cth), *Progress Report* (March 2019) 3.16.

Organisational culture

Shared supported accommodation is a home for its residents, but it is also a workplace, with its associated routines, rules and regulations. We have found this can sometimes lead to a prioritisation of staff needs and preferences, including staff safety or OH&S issues, over the needs and preferences of the residents. In turn, this can lead to a poor culture within services.

While residential settings may support a good quality of life for people with disability, there is wide variability in how residential settings are managed and whether they create an environment that is protective of human rights. Entrenched abuses in service systems and poor evidence of change in response to various inquiries into abuse and neglect indicate that a different approach is needed.[168]

Under the NDIS Commission's auditing program, an auditor will invite information about service quality directly from NDIS participants or their natural support networks (with participant consent).[169] However, we remain cautious that auditing typically focuses upon the degree of compliance with government policy, according to a predetermined set of guidelines and regulations.[170] This is different to evaluation, which encompass open dialogue and reflection with people with disability about how to improve the quality and effectiveness of supports.[171]

Our office recently undertook a pilot research project, 'Building safe and respectful cultures' that aimed to learn more about the culture of services for people with disability and to identify some practical approaches in primary prevention of abuse.[172] After speaking with people with disability, family members, staff, and managers we learnt that people with disability felt they had little personal capacity to positively change their circumstances; families and disability support workers similarly lacked agency in their roles.[173]

We found that staff and management are typically keen to have more guidance on what they were doing well and what they could improve on in relation to their organisational culture. In our research, it was the development of strong mutually rewarding relationships that was critical to the culture within services. In particular, the community of practice approach and use of music therapy in the workshops created a sense of equality and community and helped all participants to hear perspectives and concerns from others more clearly.[174]

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168. Sally Robinson et al, *Building safe and respectful cultures in disability services for people with disability* (Report for the Disability Services Commissioner, June 2019) 26.

169. Graeme Head (11 February 2020) *Witness Statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* [142].

170. Sally Robinson & Lesley Chenoweth, 'Preventing abuse in accommodation services: From procedural response to protective cultures' (2011) 15(1) *Journal of Intellectual Disabilities* 63, 69.

171. Ibid.

172. Sally Robinson et al, *Building safe and respectful cultures in disability services for people with disability* (Report for the Disability Services Commissioner, June 2019).

173. Ibid 112.

174. Ibid 130.

The research showed that building safe and respectful cultures also requires a focus on learning about the early indicators of concern; including the small indignities and low-level worries impacting people with disability.[175] The sharing and discussion of personal experiences enabled people to recognise potential patterns that should be addressed to improve service delivery as early as possible. It also prompted their action and minimised the likelihood of violence, abuse, neglect and exploitation from occurring.[176]

> **Recommendation 42:**
> That the NDIS Commission consider highlighting the report by our office, *Building safe and respectful cultures* as a community of practice approach and collaborative methodology that can be used to improve organisational culture within disability services, and to identify and address early indicators of violence, abuse, neglect and exploitation.

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175. 'Early indicators of concern' were developed as part of research in disability services in the United Kingdom to prevent abuse from occurring. The indicators are a tool to record concerns and put them together with other observations to catch concerns early.
176. Sally Robinson et al, *Building safe and respectful cultures in disability services for people with disability* (Report for the Disability Services Commissioner, June 2019) 130.