Office of the Public Advocate

Safeguarding the rights and interests of people with disability

Submission to the

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

Rights and attitudes issues paper

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Dr Colleen Pearce AM
Public Advocate
Office of the Public Advocate

Dr John Chesterman
Deputy Public Advocate
03 9603 9567
John.Chesterman@justice.vic.gov.au

Office of the Public Advocate
Level 1, 204 Lygon Street, Carlton, Victoria, 3053
Tel: 1300 309 337
www.publicadvocate.vic.gov.au

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Abbreviations

CEO	Chief Executive Officer
COAG	Council of Australian Governments
CRPD	United Nations Convention on the Rights of Persons with Disabilities
OPA	Office of the Public Advocate (Vic)
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
VALID	Victorian Advocacy League for Individuals with Disability
VCAT	Victorian Civil and Administrative Tribunal

Recommendations

Recommendation 1
Governments and the National Disability Insurance Agency and the NDIS Quality and Safeguards Commission should continue support for cultural-change training for disability service providers, which seeks to counter violence, abuse, neglect and exploitation, such as the zero-tolerance initiatives.

Recommendation 2
The Disability Ministers' forum should consider the national evaluation of Community Visitors Programs and endorse its recommendations.

Recommendation 3
Governments should strengthen human rights protections by funding peer support, self advocacy and individual advocacy at a level commensurate with demand, by substantially extending the National Disability Advocacy Program.

Recommendation 4
The Australian Government should commit to funding advocacy programs as a crucial NDIS safeguard. Such programs and funding should remain separate from any funded supports that are provided to individual NDIS participants.

Recommendation 5
Governments should strengthen human rights protections to make 'choice and control' more meaningful by funding a range of supported decision-making initiatives. This can be achieved by making it possible for NDIS participants to purchase such supports through their NDIS plan.

Recommendation 6
The Australian Government should implement the Recommendations of the Australian Law Reform Commission in its 2014 report *Equality, Capacity and Disability in Commonwealth Laws*.

1. Introduction

The Office of the Public Advocate (OPA) is a Victorian statutory office, independent of government and government services, that works to safeguard the rights and interests of people with disability. The Public Advocate is appointed by the Governor in Council and is answerable to the Victorian State Parliament.

OPA provides a range of services for people with cognitive impairment or mental illness, including guardianship, advocacy, and investigation services. In 2019-20, OPA was involved in 1792 guardianship matters (950 of which were new), 430 investigations, and 284 individual advocacy matters. The majority (72 per cent) of eligible guardianship clients were NDIS participants, compared with 58 per cent in the previous year. These figures include the 22 individuals who received guardianship and/or advocacy in the transition to community living following the closure of Colanda Residential Services in Colac.

OPA conducts investigations under the *Victorian Civil and Administrative Act 1998* (Vic) to assist the Victorian Civil and Administrative Tribunal (VCAT) in determining guardianship applications.

The Public Advocate also has a decision-making role under the *Medical Treatment Planning and Decisions Act 2016* (Vic). The medical treatment decisions team responds to requests for the Public Advocate to make decisions and in 2018-19, the team responded to 466 applications for a medical treatment decision.

Under the *Guardianship and Administration Act 2019* (Vic), OPA is required to promote and facilitate informed public awareness and understanding about substitute decision-making laws and any other legislation affecting persons with disability.[1] Last financial year, OPA's telephone advice service answered 13,644 calls, of which 17 per cent related to medical consent, medical treatment, advance care planning, and end of life issues. OPA coordinates a community education program for professional and community audiences across Victoria to engage on a range of topics including the role of OPA, guardianship and administration, enduring powers of attorney, and medical treatment decision-making.

OPA is supported by more than 700 volunteers across four volunteer programs, including the Community Visitors Program, Community Guardian Program, Independent Third Person Program and Corrections Independent Support Officer Program.

Community Visitors are empowered by law to make announced or unannounced visits to Victorian accommodation facilities for people with disability or mental illness. They monitor and report on the adequacy of services provided in the interests of residents and patients. They ensure that the human rights of residents or patients are being upheld and that residents are not subject to abuse, neglect or exploitation. In their annual report, Community Visitors report to the Victorian Parliament on the quality and safety of the services they visit.

There are more than 400 Community Visitors who visit across three streams: disability services, supported residential services, and mental health services. In 2018-19, Community Visitors made 5,527 statutory visits across all three streams.[2]

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[1] The *Guardianship and Administration Act 2019* (Vic) commenced on 1 March 2020, replacing the 1986 Act.

[2] Office of the Public Advocate, *Community Visitors Annual Report 2018-19* (2019).

2. Purpose

The purpose of this submission is to respond to the *Rights and attitudes Issues Paper,* published by the Royal Commission into Violence, Abuse, Neglect and Exploitation of people with Disability (the Royal Commission) on 28 April 2020.

3. OPA's engagement with the Royal Commission

OPA welcomes this further opportunity to contribute to the Royal Commission.

OPA's more recent written submissions have included responses to issues papers on:

- health care for people with cognitive disability
- criminal justice system
- emergency planning and response.

This OPA submission responds to some of the matters raised by the *Rights and attitudes Issues Paper* but also refers the Royal Commission to previous submissions made to it which speak specifically to matters relating to rights and attitudes in relation to those topics. Many of the recommendations made in those submissions are relevant to this issues paper. As such, the recommendations contained in this submission are more limited.

Issues associated with rights and attitudes have been integral to all of OPA's previous submissions. For example, the submission in response to *The Criminal Justice System Issues Paper* highlighted the 2012 Australian Human Rights Commission (AHRC) landmark report, *Equal before the law*. This report identified five barriers preventing people with disability from accessing justice on an equal footing with others. The first of these identified barriers is negative attitudes and assumptions about people with disabilities.

As part of this submission, OPA adopts a human rights approach that is comprehensively described later in this submission.

4. Rights awareness and ableism

In the years since OPA was established in 1986, there has been a much wider recognition of the rights of people with disability, in association with continuing advocacy and the rise of the Disability Rights Movement.[3]

In a double-edged way, increased public awareness of the rights of people with disability has occurred through the episodic revelation of large-scale and systemic abuse and neglect of people with disability in institutions and 'care' facilities. This increased awareness is also associated with the movement towards deinstitutionalisation.

In Victoria, countering large-scale systemic abuse of people with disability was the subject of intermittent campaigns conducted by newspapers, such as *The Age*'s 'Minus Children' campaign in the 1970s. Newspaper campaigns were encouraged by early advocacy organisations and informed by a global shift away from institutions to 'normalisation'.[4]

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[3] Mark Feigan, 2011. The Victorian Office of the Public Advocate: a first history 1986 – 2007. pp 53-79

[4] Ibid, p 34.

Normalisation can come in many forms. The 2016 Victorian Parliamentary *Inquiry into abuse in disability settings* found that:

> Normalisation of abuse is a fundamental barrier to identifying, reporting and investigating abuse appropriately – this is a systemic issue that requires significant cultural change on the part of [DHHS], service providers and the criminal justice system.[5]

Periodic public revelations of the violence, abuse, neglect and exploitation done to people with disability and people with a mental illness continue to shock the Australian community and provoke governmental responses. The Royal Commission itself is one such response to continuing reports and calls for action.

It is of critical importance that the long cycle of continuing violence, abuse, neglect and exploitation—punctuated by periodic public scandals and calls for action—be halted by proper address of its root causes. The Royal Commission can be a catalyst for lasting social change, so that the right of people with disability and a mental illness to lead a fulfilling life, free of violence, abuse, neglect and exploitation becomes fully embedded in the Australian community.

For this to occur, there needs to be a series of changes, guided by the core values of our liberal democracy and the shared ethic of a ‘fair go’. Many aspects of our society will be implicated, including the role and practices of service systems.

However, while high-quality human services are necessary and important, they cannot provide ‘love, commitment, fidelity and friendship’. The expectation that human services should have an all-encompassing role encourages the view that ordinary members of the community have no role to play for ‘those people’ who need ‘special care’.[6] The continuing presence in Australia of these underlying attitudes and beliefs was recently encapsulated by Professor Sally Robinson who is reported to have said:

> As a community, we probably think that people are looked after by our systems, but it's not actually the place of systems to take care of people.[7]

The same report also attributes the following statements to the CEO of the South Australian Council of Social Service, Ross Womersley:

> We have to embrace people, we have to decide that people who live with disability, who might be vulnerable are in fact of value to us as a community… If we were really thinking of them as valuable human beings we would have them present in all the aspects of our lives… By being present, people would be much more likely to build relationships, not necessarily because they're paid to be with them… The more that people are kept separate, the less they have the opportunity to make those relationships that we all rely on to stay safe and secure through most of our lives.[8]

In the report, Sarah Byrne says of her own experience: “I get upset when people don't include me into things, I feel frustrated, confused as well, that makes me sad. I get left out.”[9]

This underlying belief that people with disability are fundamentally different and of less value than other people is ableist thinking, as is recognised in the Issues Paper. Ableism is

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[5] Family and Community Development Committee, Parliament of Victoria, *Inquiry into Abuse in Disability Settings* (2016) 61.

[6] A.J. Hildebrand, 2004. One Person at a Time: Citizen Advocacy for People with Disabilities.

[7] Helen Frost, 2020. Disability inclusion should involve more community connections, Sarah Byrne believes. ABC

[8] Ibid.

[9] Ibid.

perpetuated by viewing disability through a medical-model lens rather than a capability-based approach.

4.1. Capability-based approach

The approach OPA takes and recommends for challenging exclusionary beliefs and assumptions is informed by the capability-based approach to flourishing human life, developed by Amartya Sen and Martha Nussbaum.[10]

In this framework, a flourishing life has these elements:

- **affiliation:**
    - **being able to live with and toward others**: recognising and showing concern for others; engaging in social interaction; being able to imagine the situation of another.
    - **having the social basis for self-respect and non-humiliation**: being treated as a dignified being whose worth is equal to that of others – this entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin and species.
- **bodily health**: having good health, including reproductive health; being adequately nourished; having adequate shelter.
- **bodily integrity**: being able to move freely from place to place; being secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and choice over contraception and reproduction.
- **control over environment**:
    - **material**: being able to hold property (both land and movable goods); having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having freedom from unwarranted search and seizure; having meaningful work where you can exercise practical reason and your human potential; having meaningful relationships and mutual recognition with other workers.
    - **political**: being able to participate effectively in political decisions that govern life; having the right of political participation; protections of free speech and association.
- **emotions**: have attachments to things and people outside of yourself; generally, to love, grieve, experience longing, gratitude, and justified anger; not having your emotional development hindered by fear and anxiety; supporting forms of human association that are crucial to a person's emotional development.
- **life**: living a normal human life span; not dying prematurely or having life reduced to a life not worth living.
- **other species**: being able to live with concern for and in relation to animals, plants, and the world of nature.

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[10] M.C. Nussbaum, 2006. *Frontiers of justice: disability, nationality, species membership*. A. Sen, 2009. *The idea of justice*.

- **play**: being able to laugh, to play, to enjoy recreational activities.
- **practical reason**: being able to form a conception of the good and to engage in critical reflection about the planning of one's life.
- **senses, imagination and thought**: being able to use the senses; to be able to imagine, think, and reason broadly, informed and cultivated by an adequate education, including literacy and basic mathematical and scientific training; being able to use imagination and thought in connection with wide ranging experiences, including religious, literary, musical, and other works and events; being able to use your mind in ways protected by guarantees of freedom of expression, including political and artistic speech, and freedom of religion; having pleasurable experiences and being able to avoid non-beneficial pain.[11]

In Victoria, many of these capabilities for a flourishing life already have formal recognition through the *Charter of Human Rights and Responsibilities Act 2006* (Vic) (Charter) and other legislation.[12] OPA sees the elements of a flourishing life as a guide for developing inclusionary human-rights based approaches.

4.2. A human rights approach

A human-rights approach begins by recognising people with disability as rights bearers, both moral and legal. Uppermost is respect for the dignity of people with disability. As was recently stated by the Australian Human Rights Commission, international human rights treaties offer the most widely accepted framework for protecting individual dignity and promoting the flourishing of communities.[13] The United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) states what must be done to provide dignity for all people with disability.

A human-rights approach affirms the inherent worth of every individual and promotes and protects universal rights. A human rights approach provides real equal opportunity, effective participation and full inclusion in society. It also involves creating a culture, both broadly in society and within organisations, that fosters a human-rights approach mindset. Culture is the product of our values and our actions, including the words we use.

Ultimately, further regulation is required as a human rights approach does demand some significant changes to laws, policies and practices. In Victoria, some internationally recognised civil and political rights are enacted through the Charter[14] but OPA is aware that in Australia only Victoria and the ACT have a human rights charter.

At the policy level, a human-rights approach can be understood as providing a platform for:

- accountability measures for state actors with responsibilities
- building community capacity, including promotion of respect for human rights in the non-government sector and the community
- ensuring non-discrimination and equity
- measures that provide the capacity for influencing government decisions
- participatory approaches
- responding to the specific and individual needs of people with disability

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[11] C. Babin. (n.d.) *Disability Rights, Dr. Martha Nussbaum's 10 capabilities*.
[12] *Charter of Human Rights and Responsibilities Act 2006* (Vic).
[13] Australian Human Rights Commission, 2019. *Human rights and technology discussion paper.* p.31
[14] Charter of Human Rights and Responsibilities Act 2006 < http://www5.austlii.edu.au/au/legis/vic/consol_act/cohrara2006433/>.

- specifying obligations of other bodies with responsibilities. [15]

OPA proposes the above elements should be integrated into policy and legislation to give people and organisations a point of reference for ensuring their practices are advancing the human rights of people with disability.

4.3. Discriminatory attitudes within systems

OPA and Community Visitors observe that persistent and destructive discrimination lingers in major social systems of care, as is demonstrated by the experience of people with disability. In past submissions made to the Royal Commission, OPA described in detail how discriminatory attitudes are present in the health system, the criminal justice system, and in emergency planning and responses in relation to the Victorian bushfires and the current pandemic. OPA has previously described the systemic abuse that pervades the child protection system, and to an extent the family law system, in numerous publications and plans to make a submission to the Royal Commission on these important matters.

That discriminatory attitudes are ingrained in our service systems is largely owed to the sometimes-pervasive discriminatory attitudes—described in OPA's previous submissions—which can be held by practitioners and policy-makers; like other members of the community, an illustration of the depth and extent of this significant and deeply entrenched social problem, and the inequities they can lead to in service delivery.

In relation to the NDIS, for instance, the (Tune) Review of the *National Disability Insurance Scheme Act 2013* (Cth) (NDIS Act) found that even within the disability sector, people with disability are still not being recognised as the biggest expert on their disability, contrary to the NDIS' rhetoric of choice and control.[16] The appropriate shift to determining disability services and eligibility for the NDIS based on functional need is undermined by attitudes and outmoded practices adopted by the NDIA, for instance, its perceived need for 'paperwork' evidence from medical practitioners providing a diagnosis to "demonstrate they have a permanent disability that affects their everyday life."[17] Concerns are emerging within the sector in relation to the announcement from the NDIA that participants will be required to use NDIA-approved practitioners to have assessments funded that are required to determine their eligibility to the scheme.

4.4. The understanding of disability

Significant work needs to be done to shift the understanding of disability so that all Australians, including service and mainstream workforces, move towards seeing that authority lies in the experience of the person with disability.

OPA talks further about this and related issues in its submission to the (Victorian) State Disability Plan 2021- 2024 consultation paper, available on OPA's website.[18]

For example, in that submission OPA provides the following response to the question of how the next state disability plan should set out a description of disability and a human rights approach:

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[15] Australian Human Rights Commission, 2019. *Human rights and technology discussion paper*, pp.29-31, which draws on the UN Guiding Principles on Business and Human Rights.

[16] Department of Social Services, 2020 <https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-national-disability-insurance-scheme/2019-review-of-the-ndis-act-and-the-new-ndis-participant-service-guarantee>.

[17] NDIS, 2019 <https://www.ndis.gov.au/applying-access-ndis/how-apply/information-gps-and-health-professionals>. OPA talked further about this issue in its response to the consultation on the Victoria State Disability Plan 2021 – 2024.

[18] Office of the Public Advocate, *Submissions* <https://www.publicadvocate.vic.gov.au/resources/submissions/2020-submission-to-the-state-disability-plan-20212024-consultation-paper> May 2020.

OPA supports having a contemporary definition of disability, noting that the understanding of disability has evolved over time.[19]

In this section, we propose a method for defining disability and a connected human rights approach [referred to in this submission directly above].

OPA believes the definition of disability should be broad, without weakening the meaning of the term so that it still provides a focus for the measures demanded by the United Nations *Convention on the Rights of Persons with Disabilities.* It remains necessary to move away from the medical model. There is an over-dependence on medical diagnosis and explanation to identify disability and regulate entry to measures for people with disability.

Although the experience of disability has near universal features for all humans, the sustained lived experience of disability and its systematic devaluation is not universal. People without disability may gain substantial insights into the disability experience. This can be through episodes and relationships in a person's life, without giving rise to a disability identity. A disability identity comes only from the (changing) long-term experience of living with impairment (which also may be episodic or fluctuating) and the barriers and experiences encountered in life as a result. This experience gives rise to a disability identity (self-generated or ascribed), as one facet of an individual's complex and evolving identity.

The appropriate shift to determining disability service and NDIS access based on functional need is being undermined by attitudes and outmoded practices. This is occurring because of the perceived need for 'paperwork' evidence from medical practitioners providing a diagnosis to 'demonstrate they have a permanent disability that affects their everyday life'.[20]

Work needs to be done to shift the understanding of disability so that all Victorians, including service workforces, move towards seeing that authority lies in the experience of the person with disability. As was found in the (Tune) Review of the NDIS Act, people with disability are still not being recognised as the biggest expert on their disability, contrary to the rhetoric on choice and control.[21]

To help shift attitudes, it is necessary to formally adopt a relational approach to defining disability, rather than the frequent list-based approaches.[22]

At its simplest, a person with disability is a person who identifies as having a disability. Some people with disability will be consistently identified by others in a close relationship with them as having a disability. The latter should not occur where the person has the capacity to adopt or refuse this identity themselves. This is the approach that most people already take in everyday life and it should be mirrored in policy.

For some people with disability, their disability identity and support needs will need to be documented. They will want or need this to occur for purposes of access to

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[19] Julia Korolkova and Alexandria Anthony, 2016, *The United Nations Convention on the Rights of Persons with Disabilities and the right to support*, Melbourne Law School.

[20] NDIS, 2019 <https://www.ndis.gov.au/applying-access-ndis/how-apply/information-gps-and-health-professionals>.

[21] Department of Social Services, 2020 <https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-national-disability-insurance-scheme/2019-review-of-the-ndis-act-and-the-new-ndis-participant-service-guarantee>.

[22] An example of a list-based approach is the disability definition used in the *Guardianship and Administration Act 2019:* disability in relation to a person, means neurological impairment, intellectual impairment, mental disorder, brain injury, physical disability or dementia.

reasonable adjustments or formal supports. Such an approach, for formalised recognition, could be straightforward, involving a combination of three elements.

The first element is either self-identification of their disability identity by the person, or recognition of this identity by others in close relationship with the person. The second element involves the person (or their supporter) describing their functional supports needs, resulting from impairment. The third element is acceptance and documentation of the person's described support needs by those having a support relationship with the person.

The documentation of functional support needs could be self-administered using a recognised system, or a collaborative process with people bringing an expertise desired or needed by the person. This approach could utilise existing standardised disability-identification systems and checklists, while remaining open to future developments.

By itself, engaging in this documentation process would not result in formal certification, but the results of the process would be documented and registered when and where required. Doctors or allied health professionals may be of assistance in this process, but their involvement would not be mandatory for the simple process of recognising a person as living with disability and having functional support needs.[23]

5. Changing discriminatory attitudes

One of the first steps to help shift discriminatory attitudes is to formally adopt a relational and capability-based approach to defining disability (as described above), rather than the frequent list-based approaches, which divide people into impairment-based categories.[24]

Community attitudes are held by community members and embedded in laws, regulations, customs and practices. The lack of inclusion due to the non-provision of universal design constitutes discrimination against people with disability. The lack of universal design helps foster the 'us and them' mentality.

Both providing universal design and working towards changing discriminatory community attitudes are the responsibility of government in all of its activities, policies and programs. This requirement and monitoring of progress must be mandated, enacted through revamped legislated requirements upon all governmental authorities. One way to achieve this would be to revisit the *Disability Discrimination Act 1992* (Cth) (Disability Discrimination Act) provisions for disability action plans.

5.1. Reviving disability action plans

The Disability Discrimination Act is a good foundation for promoting the rights of people with disability and reducing discriminatory attitudes. The objects of the Act are:

> (a) to eliminate, as far as possible, discrimination against persons on the ground of disability in the areas of:
>
> (i) work, accommodation, education, access to premises, clubs and sport; and
> (ii) the provision of goods, facilities, services and land; and
> (iii) existing laws; and

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[23] Office of the Public Advocate, *Submissions*, May 2020 <https://www.publicadvocate.vic.gov.au/resources/submissions/2020-submission-to-the-state-disability-plan-20212024-consultation-paper> 8-9.

[24] An example of a list-based approach is the definition of disability used in the *Guardianship and Administration Act 2019* (Vic)*:* disability in relation to a person, means neurological impairment, intellectual impairment, mental disorder, brain injury, physical disability or dementia.

(iv) the administration of Commonwealth laws and programs; and

(b) to ensure, as far as practicable, that persons with disabilities have the same rights to equality before the law as the rest of the community; and

(c) to promote recognition and acceptance within the community of the principle that persons with disabilities have the same fundamental rights as the rest of the community.[25]

However, nearly thirty years since the commencement of that Act and its promise has not been fully realised as discrimination against people with disability pervades.

Part 3 of the Disability Discrimination Act contains provisions for Disability Action Plans for devising approaches to achieving the objects of the Act. In Victoria, the *Disability Act 2006* (Vic) broadens the mandate, scope and effect of disability action plans.[26] The Disability Act also mandates the Victorian State Disability Plan, which is a key State instrument for delivering the National Disability Strategy.[27]

Strengthening existing frameworks could provide a way forward. Disability action plans in their present form have led to many improvements in access to goods and services. They continue to have a role. The issue with disability action plans is that they can be lifeless or exceedingly modest in aspiration.

A cursory examination of the list of action plans on the Australian Human Rights Commission register shows they are not working effectively across all sectors, with many being past date.[28]

In Victoria, the mechanism needs new life breathed into it and OPA suggests the most effective way to reinvigorate disability action plans will come through the application of performance measures with positive and negative sanctions. For example, the Victorian Government, through the State Disability Plan outcomes framework, is developing a valid and reliable data set using measures and indicators that can be used to track progress against the plan’s objectives. These measures could be further developed and work could be done nationally, so that all governmental organisations are required to adopt meaningful performance targets that are consistent with the revised outcomes framework.

Organisations would then be held accountable for their performance against the agreed measures. This approach could require an enhanced coordination and overseeing role. Well performing organisations could be recognised and rewarded. Under performing organisations could be held up to scrutiny.

5.2. National Disability Strategy

The further elements of a human-rights approach, referred to above as the capability-based approach, can be translated into revised arrangements for the protection of human rights in the next National Disability Strategy. To expand the Strategy in this way would guide the ways that individuals, communities and organisations respond to people with disability in ways that are consistent with the CRPD.

The next National Disability Strategy can be the roadmap for a process of implementing and evaluating progress towards resourcing people with disability to lead a flourishing life. This is a natural progression from the vision of the current Strategy, which is of ‘an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens’.

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[25] *Disability Discrimination Act 1992* (Cth) s 3(a)–(c).

[26] *Disability Act 2006* (Vic).

[27] Victorian Government, 2016. *Absolutely everyone: state disability plan 2017-2020*.

[28] Australian Human Rights Commission, Register of Disability Discrimination Act Action Plans.

5.3. Disability Ministers' Forum

The Prime Minister recently announced that the Council of Australian Governments (COAG) is to be formally replaced by the National Cabinet and that further changes will flow on to governmental governance structures following a review by the National Cabinet.

The COAG Disability Reform Council will be affected and "while the review is underway, disability ministers continue to meet to discuss critical issues of national significance in accordance with agreed protocols and the NDIS Act. The future form and role of a disability ministers' forum will be determined under the revised Ministerial Forum structure, including progressing of current actions."[29]

The most recent COAG Disability Reform Council Terms of Reference were agreed to in 2019.[30] The role of the Disability Reform Council includes critical responsibilities for issues and intergovernmental agreements including:

- National Disability Strategy 2010-2020
- National Disability Agreement
- National Disability Insurance Scheme matters
- ensuring mainstream policy, program and service delivery improves outcomes for people with disability
- ensuring arrangements are in place so that Indigenous people with disability have access to services and facilities and achieve improved outcomes comparable to other people with disability, especially in remote and very remote areas
- considering the impact of regulation on individuals, community organisations and businesses, and identify opportunities to reduce or remove this burden wherever possible
- establishment and progress of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

OPA hopes that the important role of the Disability Reform Council will continue and be improved under the new Ministerial Forum structure. Disability Ministers', as a group, should be the vehicle for improving the National Disability Strategy as a platform for human-rights based approaches across all governments and extending to the wider community.

6. Improving attitudes in the health system: An example

OPA includes the following section to describe its *Healthy Discussions* project as a concrete and practical example of the work that can be (and is) undertaken to shift attitudes towards people with disability.

To provide context to this issue—and a further example—OPA refers here to the learnings from its Medical Decisions Team, as it directly encounters issues relating to attitudes, which create barriers to equality and inclusion. Under the *Medical Treatment Planning and Decisions Act 2016* (Vic), people can make their own medical treatment decisions, providing they have decision-making capacity to do so.[31] A person with a significant disability may have decision-making capacity if provided with the support they need to make that decision. Examples of such support include taking additional time, using modified

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[29] Meeting of Commonwealth, State and Territory Disability Ministers (Government of Australia). *Statement* (24 July 2020).

[30] Council of Australian Governments, 2019. COAG Disability Reform Council, 2019 Terms of Reference.

[31] *Medical Treatment Planning and Decisions Act 2016* (Vic).

language or visual aids, and engaging a supporter who assists by discussing information or helping to communicate a decision.[32]

The OPA Medical Decisions Team find they sometimes need to negotiate a paternalistic medical-model approach by health practitioners, which creates a barrier to equality and inclusion in the patient's healthcare. They sometimes find professionals still presume a substituted decision-making approach based in perceived best-interests, rather than seeking guidance in the person's preferences and values.

Where necessary, the Medical Decisions Team address pervasive attitudes and beliefs with education and advocacy directed at health practitioners and other professionals. The team regularly works with health practitioners and other professionals to ensure that each patient is given equal opportunities and is respected and supported to participate in their health care and medical treatment.

OPA also has a dedicated medical advice line to provide guidance and education for health professionals.

Some of the practical ways in which the Medical Decisions Team and OPA's Advice Service advocate for patients they are involved with, or who OPA receives enquiries in relation to, is by:

- educating the health practitioner on the legislation and their obligations
- providing advice and guidance on decision-making capacity; particularly, that decision-making capacity is decision specific and should be assumed unless there is evidence to the contrary
- communicating that the making of a diagnosis does not automatically mean that the person is not given the opportunity to understand, weigh up and retain information about the proposed medical treatment
- ensuring that limitations of the offer of treatment or the exploration of potential future treatment options are not due to discriminatory attitudes or assumptions
- ensuring that limitations of the offer of treatment or the exploration of potential future treatment options are not due to assumptions or suggestions that the person may not be compliant, based on past experiences or behaviours
- ensuring that end-of-life, ceiling-of-care or futile-and-non-beneficial-treatment decisions are solely clinical decisions, based on a patient's clinical status and their prognosis. This also ensures such decisions are not discriminatory or based on unfounded quality-of-life assumptions or attitudes.
- providing and disseminating resources, such as OPA Fact Sheets, to enhance knowledge and understanding
- promoting less restrictive options, for example a section 63 request under the *Medical Treatment Planning and Decisions Act* to the Public Advocate for consent, rather than a guardianship application
- providing guidance on decision making when a person is a patient under the *Mental Health Act 2014* (Vic).[33]

OPA's new project, *Healthy discussions: Supporting people with disability to make and communicate health decisions*, provides a different example of how to tackle entrenched

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[32] OPA and Reinforce, 2019. *The right of people to make their own decisions* <https://www.publicadvocate.vic.gov.au/resources/fact-sheets/medical-decisions/644-the-right-of-people-to-make-their-own-medical-decisions>.

[33] OPA Medical Treatment Team, Internal communication.

discriminatory attitudes. It is a two-year project funded by a Mainstream Capacity Building Grant of the National Disability Insurance Scheme.[34]

The project aims to support health professionals throughout Victoria (particularly health professionals in the public sector) and those training to be health professionals, to improve their communication with, and understanding of, people with disability who have specific communication needs.

By using a supported decision-making lens, the project activities will highlight that in Victoria everyone with capacity to do so has the right to make their own decisions about their health and, to the extent possible, people should be provided with the support they need to make these decisions.

The project will also highlight that small but effective initiatives by health professionals can go a long way in supporting people with disability to ensure they are at the centre of decisions about their own health.

The project uses a best-practice model of people with disability being involved in the design and delivery of the project in a paid capacity. The heart of the *Healthy Discussions* project is the voice of people with disability. People with lived experience of intellectual disability, acquired brain injury and autism are integral to the project, including as members of the project steering committee. As part of the project, OPA will also employ two people who have lived experience of intellectual disability, acquired brain injury or neurological impairment (such as autism) and who have experience as self advocates. Narratives of lived experience will be a feature of the project. It will showcase the skills and abilities of the project workers with lived experience of intellectual disability, acquired brain injury or neurological impairment. This is a key component of the project because research shows that positive contact with people with disability changes attitudes.[35]

The *Healthy Discussions* project builds on the 2019 joint project with Reinforce Self Advocacy, which was funded by the Victoria Law Foundation. This was also a co-design project. As part of that project, OPA and Reinforce created a brochure for doctors that includes examples of three people's experiences with doctors and hospitals.[36]

As part of the *Healthy Discussions* project, OPA will:

- engage with self-advocacy organisations run for and by people with disability to let these organisations know about the project and to hear from these organisations
- engage with representatives from health organisations, networks and peak bodies, and organisations providing education and information to current or future health professionals. At the heart of this engagement will be the voice of people with lived experience of intellectual disability, developmental disability and acquired brain injury.
- establish a Practice Showcase Network for organisations undertaking similar initiatives to share learnings that can improve the inclusiveness and accessibility of health services
- deliver education webinars and presentations to health professionals and future health professionals, including in rural or regional locations. The sessions will

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[34] NDIS 2020, Summary of funded activities.

[35] Melanie Randle and Samantha Reiss, 2016. *Changing community attitudes toward greater inclusion of people with disabilities*.

[36] OPA and Reinforce, 2019. *The right of people to make their own decisions* <https://www.publicadvocate.vic.gov.au/resources/fact-sheets/medical-decisions/644-the-right-of-people-to-make-their-own-medical-decisions>.

include narratives of people with lived experience of disability and a presenter with lived experience of disability.

- develop short video scenarios highlighting the lived experiences and people with disability. These videos will be used in education presentations, will appear on the OPA website, and will be promoted in the OPA Updates electronic newsletter.

OPA is thrilled to be working on this project with Reinforce Self Advocacy.

7. Culture

It is useful here to consider important insights from social psychology. The evidence from key social psychology studies is that violence, abuse, neglect and exploitation are the consequence of situational and systemic forces that influence and permit the behaviour of individuals. Rather than 'bad apples', it is 'bad barrels' that are the problem.[37]

The everyday understanding of disability recognises the broad diversity of people with disability that dedifferentiated public policy has obscured.[38] There is a vast repertoire of stigmatising historical terms to refer to people with disability with different impairments. Different attitudes and levels of discrimination and exclusion are tied to these various labels. Entrenched habits of language, attitudes and exclusion are 'bad barrels'.

It is likely that the deep-seated social change that needs to occur to shift everyday attitudes is a multi-generational process. It is now about fifty years into this process of social change. It is to be hoped that much speedier progress can be made in the next decade, following the insights that the Royal Commission will deliver.

The advantages of dedifferentiated policy must be persevered with,[39] while further adaptations and adjustments are made to successfully include all people with disability. A major adaptation that is required but has still not been realised is the shift to greater recognition and practical arrangements for supported decision-making, further discussed in the next section. The best challenge to deeply-rooted exclusionary attitudes and prejudices is everyday contact with people with disability. That is why the movement towards social and economic inclusion is so critical and must be accelerated.

7.1. Culture within disability residential services

Since 1987, Community Visitors in Victoria report on the events of violence, abuse, neglect and exploitation that they encounter through their visitation of disability residential services, acute inpatient mental health services and Supported Residential Services (SRS). OPA's report *"I'm too scared to come out of my room" Preventing and responding to violence and abuse between co-residents in group homes*, submitted to the Royal Commission as part of its response to the *Group Homes Issues Paper*, seeks to understand and resolve the issue of violence between co-residents in group homes. The Royal Commission heard first hand from the Public Advocate and two Community Visitors at its December 2019 hearing on this topic.

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[37] Philip Zimbardo, 2007, The lucifer effect: how good people turn evil.

[38] Professor Chris Bigby has recently explored some of the key issues related to the dedifferentiation of public policy that has occurred since the 1980s, in relation to intellectual disability: "For people with intellectual disabilities, dedifferentiation emphasises each individual's needs and functional abilities and their membership of the generic group 'people with disabilities', rather than the impairment-specific group 'people with intellectual disabilities"': Christine Bigby, 2020. *Dedifferentiation and people with intellectual disabilities in the Australian National Disability Insurance Scheme*.

[39] Ibid. Professor Bigby describes the strengths of this the dedifferentiation approach, which: reflects the preference of people with mild intellectual disabilities; avoids attention to devalued differences or stigmatising labels; promotes inclusion in mainstream rather than specialist services (which historically have been of poor quality); strengthens collective advocacy by people with disability.

The Public Advocate notes that:

> Violence and abuse between co-residents with disability rarely results in the proactive, protective responses expected in family violence situations. Violence perpetrated by and towards persons with disability is not always described as such but, instead, is often described as ‘behaviours of concern’ or ‘resident incompatibility’ and dismissed.[40]

In relation to this particular issue of violence within services, Community Visitors have reported that despite the number of recent inquiries into violence against people with disability, the specific issue of violence between co-residents has received little practical attention.[41]

Community Visitors have been able to document some of the extent of this problem:

> During 2018-2019, 170 issues of abuse and neglect in disability group homes were recorded by Community Visitors, with 18 notifications made to the Public Advocate regarding the most serious. Resident-to-resident violence continues to figure prominently in reported cases, while staff-to-resident abuse is also concerning. There are multiple instances where residents have expressed to Community Visitors how fearful they are in their own homes, and how they often choose to stay in their rooms rather than interact in shared living spaces.
>
> The trend towards an increase in the number of incidents reported is also disturbing. Nearly half of all serious incidents in disability group homes reported each year relate to violence between co-residents.[42]

Resource limitations is one of the reasons for the continuing toleration of ongoing violence, abuse and neglect affecting many hundreds of people with disability. The following example from the Community Visitor Annual Report shows how the lack of alternative options and rigid systems perpetuate problems:

> One divided house where three residents reside has frequent assaults, property damage and other incidents, placing residents, staff and community members at risk. Casual and agency staff frequently fill the roster. Department of Health and Human Services (DHHS), the Disability Services Commissioner (DSC) and the Office of Professional Practice (OPP) have all been involved, but the three residents have different support coordinators and each of the residents’ families has refused the limited alternative accommodation options offered, judging them unsuitable. The situation is at a stalemate. None of the residents can easily live in shared accommodation and other accommodation options are extremely limited. Community Visitors have advocated strongly for the needs of all three to be met more effectively and will continue until a workable solution has been arrived at to benefit all three residents.[43]

Attitudes held by staff observing and intervening on ongoing abuse and neglect as well as the staff receiving their reports (whether that be management or government department staff) all contribute to maintaining the status quo. The multiplicity of service providers and the casualisation of staff now involved in the lives of people with disability living in SDA dwellings and other group homes exacerbates the vulnerability of residents. Service providers now operate in an environment that is increasingly difficult to monitor by established safeguarding bodies, such as Community Visitor schemes.

However, a big part of the problem is the failure to recognise and name these behaviours as violence, abuse and neglect rather than some other kind of issue that can be treated in a different way. This is a less readily apparent example of ‘bad barrels’ that inure well-meaning staff to the underlying reality occurring before them.[44] Recognising this, the

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[40] Collen Pearce, 2019. Report from the Public Advocate, *Community Visitors Annual Report 2018-2019* (2019) 8.

[41] Ibid 18.

[42] Ibid.

[43] Ibid 19.

[44] Philip Zimbardo, 2007. *The lucifer effect: how good people turn evil*.

Community Visitors Program in Victoria implemented abuse-detection training for Community Visitors to enhance their capacity to identify and report incidents of abuse and neglect.

The ‘zero tolerance’ approach that has been mandated in Victoria through the *Disability abuse prevention strategy* is intended to recalibrate disability service systems so that abuse is reframed as a human rights issue.[45] OPA and Community Visitors strongly support this approach and would like to see this stronger approach adopted federally via the NDIS Code of Conduct. The NDIS Code and guidance only requires service providers to make their best efforts to prevent abuse. This is not enough when safeguarding systems should place a premium on people with disability being able to live safely and free from abuse.

There needs to be a multi-faceted response to the ongoing occurrence of violence, abuse, neglect and exploitation within group homes, which includes the extension and development of Community Visitors schemes and staff training. Because of the scale of the problems, there should be high-level planning and coordination, which will require the commitment of all Governments to addressing the findings of the Royal Commission.

OPA commends to the Royal Commission the Disability Services Commissioner (Victoria) report, *Building safe and respectful cultures in disability services for people with disability*. The report was a pilot research project exploring the prevention of violence, abuse and neglect of people with disability in Victoria.

The project aimed to understand the role of culture in promoting safety and wellbeing and addressing the conditions that lead to violence, abuse and neglect in disability services. It concluded the need to prevent abuse before it starts and it identified some practical approaches that might be both useful now and relevant for future development. This important research project was co-produced, completed by a team of academic researchers, staff from the Disability Services Commissioner and community researchers including people with lived experience of disability. The project ran between June 2018 and April 2019. OPA was on the Project Advisory Group.[46]

OPA refers the Royal Commission to the raft of recommendations made in *I’m too scared to come out of my room*, OPA makes the following additional recommendations:

Recommendation 1
Governments and the National Disability Insurance Agency and the NDIS Quality and Safeguards Commission should continue support for cultural-change training for disability service providers, which seeks to counter violence, abuse, neglect and exploitation, such as the zero-tolerance initiatives.

Recommendation 2
The Disability Ministers’ forum should consider the national evaluation of Community Visitors Programs and endorse its recommendations.

8. Advocacy

Advocacy is vital to safeguarding and advancing the rights and wellbeing of people with disability. There are six main models of advocacy: self-advocacy, family advocacy, citizen advocacy, individual advocacy, legal advocacy and systemic advocacy. They all provide critical support and voice by, with, and for people with disability.

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[45] Department of Health and Human Services, 2019. *Disability abuse prevention strategy*. National Disability Services, 2018. *Zero tolerance* < https://www.dhhs.vic.gov.au/publications/disability-abuse-prevention-strategy>.

[46] Disability Services Commissioner, *Building Safe and Respectful Cultures* <https://www.odsc.vic.gov.au/abuse-prevention/building-safe-and-respectful-cultures/>.

In Victoria, the Public Advocate is empowered by the Guardianship and Administration Act to undertake advocacy for persons with disability on both a systemic and individual basis. OPA has a dedicated systemic advocacy unit to carry out the systemic advocacy function and most OPA staff members carry out advocacy on an individual basis when undertaking the functions and powers of the Public Advocate.

The *Disability Services (Principles and Objectives) Instrument 2018* (Cth) is one of the more recent iterations of legislated 'principles and objectives' discussed earlier. It includes a statement with a highly limited conception of the role of advocacy:

> Services should be designed and administered so as to ensure that people with disability have access to advocacy support where necessary to ensure adequate participation in decision-making about the services they receive.[47]

The importance of independent advocacy cannot be understated. Provision of good advocacy should be made available and accessible across all mainstream systems.

Recommendation 3
Governments should strengthen human rights protections by funding peer support, self advocacy and individual advocacy at a level commensurate with demand, by substantially extending the National Disability Advocacy Program.

With the introduction of the NDIS, the need for independent advocacy has increased, rather than diminished. The Joint Standing Committee found that "the transition to a market-based system combined with the transition of Commonwealth, state and territory programs have resulted in emerging service gaps in important areas, including advocacy, assertive outreach and support coordination".[48]

In part, on the advocacy point, this can be explained by shortfalls in funding for advocacy services. OPA appreciates that the Australian Government is leading a "national demand and gap analysis of independent disability advocacy and decision-making supports"[49] and that the findings of this work will inform Disability Ministers' in making future funding decisions for these services. It is critical that this work be promptly progressed.

There are other factors that have contributed to an increased need for advocacy, such as the limitations of the NDIS' complaints-based system where the impetus is on participants to come forward to express their dissatisfactions. OPA considers that a complaints-based system can act to disregard the range of factors that may prevent people with disability from doing so. For example, a participant may fear losing services if they come forward or, in the case of people with cognitive impairment who may not have the capacity or opportunity to articulate their concerns, a complaint can be too burdensome to initiate. This can be compounded for people who have limited informal supports in their lives.

OPA stresses the importance of representative bodies, advocacy organisations, and other consumer bodies in assisting NDIS participants to make complaints. Indeed, the NDIS Quality and Safeguarding Framework recognises the role of formal independent advocacy in ensuring adequate safeguarding and the importance of these programs being adequately resourced to support participants. It is worrisome that many advocacy organisations report being strained, operating with reduced or uncertain funding, and dealing with increasing waitlists.

Most worrisome is the failure from certain agencies in the sector to fully recognise and utilise the role of independent advocates in supporting participants. Most recently, OPA has

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[47] Disability Services (Principles and Objectives) Instrument 2018

[48] Joint Standing Committee on the NDIS, Parliament of Australia, *Transitional Arrangements for the NDIS* (2018) 70.

[49] Meeting of Commonwealth, State and Territory Disability Ministers (Government of Australia). *Statement* (24 July 2020) 1.

seen the NDIA and the NDIS Quality and Safeguards Commission deny involvement of independent advocates in supporting participants, despite it being well established in the NDIS Act that the role of advocates be recognised in supporting participants.

The role and value of advocacy is still under-appreciated, despite the high return on investment, in both monetary and human-rights terms, being significant.[50]

Recommendation 4
The Australian Government should commit to funding advocacy programs as a crucial NDIS safeguard. Such programs and funding should remain separate from any funded supports that are provided to individual NDIS participants.

9. Supported decision-making

While the advocacy support role may incorporate support for decision-making, advocacy and supported decision-making are different activities.

Supported decision-making is the provision of decision-making supports that enable persons with cognitive impairment to exercise their legal capacity by being assisted to make valid decisions. It is based on the premise that everyone has the right to make their own decisions and to receive whatever support they require to do so. When legally recognised, supported decision-making can be an empowering alternative to formal substitute decision-making.

OPA has raised supported decision-making in most of its submissions made to the Royal Commission and has a publication entitled *Side by Side* that describes supported decision-making. Here, OPA promotes it in a wider and broader sense.

OPA considers that the process of supported decision-making has two very important aims. Firstly, it aims to ensure people have the support they need to pursue their own goals, make choices about their life, and exercise control over the things that are important to them. This can be described as self-determination. Secondly, it aims to replace mechanisms of substitute decision-making by ensuring people are supported to exercise their legal capacity (make decisions with legal consequences) and remain legal decision makers (because the support they receive is legally recognised). This gives effect to Article 12 of the CRPD.

The Australian Law Reform Commission (ALRC) undertook an inquiry into *Equality, Disability and Capacity in Commonwealth Laws*, with its final report published in 2014. It continues to be a landmark report and OPA regularly advocates for implementation of its many important recommendations. OPA commends the report to the Royal Commission.

At the heart of the ALRC inquiry was its purpose to ensure people with disability have an equal right to make decisions for themselves. It was about respecting the dignity, autonomy and independence of people with disability, while supporting them to make their own decisions, where such support is needed. The ALRC understood its inquiry to reflect an important movement away from:

> viewing persons with disabilities as ‘objects’ of charity, medical treatment and social protection towards viewing persons with disabilities as ‘subjects’ with rights, who are

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[50] Anne Daley, Greg Barret and Rhiân Williams, 2017. A Cost Benefit Analysis of Australian independent disability advocacy agencies

> capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.[51]

Ultimately, the ALRC recommends a Commonwealth decision-making model and a set of National Decision-Making Principles to guide the development of new laws, policies and decision-making practice across Australia. OPA's submission to the ALRC articulated the important need for safeguards to protect the person who may require decision-making support from abuse, neglect or exploitation. One of these safeguards is articulated in the National Decision-Making principles as "decisions, arrangements and interventions for people who may require decision-making support must respect their human rights". This includes substitute decision-making.

9.1. Legislative reform

Significant legislative reform has occurred in Victoria in the area of supported decision-making. As of March 2020, there are five pieces of legislation in Victoria that legally recognise supported decision-making.[52] These Acts have created six different possible legislated roles for people to provide decision-making support. OPA strongly advocates for similar legislation to be replicated across Australia.

Across Australia, the arrangement of last resort for a person who lacks decision-making capacity and is at risk of abuse is guardianship (and administration). In its submission to the ALRC, OPA and the South Australian Office of the Public Advocate argued the following:

> the danger that an 'overemphasis' on a person's autonomy may be 'to the detriment of protection for people who need guardianship as a rights enhancing mechanism' … guardianship, properly done, is a positive use of state power that enhances the inclusion and legal personhood of the represented person'.[53]

OPA notes that guardianship across Australia is changing in response to international developments in understanding the rights of people with disability in the 21st century, namely the paradigm shift "demanded by the CRPD".[54] Both the object and general principles of the new (Victorian) Guardianship and Administration Act reflect an important shift in thinking bought about by the CRPD. OPA notes, importantly, the Act maintains a protective role in the ability of VCAT to appoint a guardian (and administrator) and that this form of substitute decision-making should, as far as practicable, be directed by the will and preferences of the person with disability. OPA further notes that the Act recognises that there may be situations that call for overriding the person's will and preferences to prevent serious harm.[55] This links directly with the function of the Public Advocate to protect persons with disability from abuse, neglect and exploitation.[56] OPA is pleased to see provisions in the Act for the appointment of supportive guardian (and supportive administrator) and hopes that this will lead to a reduction in the need for substitute decision-making.

One of the key challenges in relation to supported decision-making is that ideally, support is provided by a trusted person. Some people with disability, sometimes particularly people with significant cognitive impairment, have limited informal supports in their life to take on

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[51] Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Report 124, 2014, 23, citing United Nations Enable-Secretariat for the CRPD, *Convention on the Rights of Persons with Disabilities* <www.un.org/disabilities>.

[52] They are the *Powers of Attorney Act 2014, Mental Health Act 2014, Medical Treatment and Planning Decisions Act 2016, Guardianship and Administration Act 2019, National Disability Insurance Scheme Act 2013* (Cth).

[53] Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Report 124, 2014, 60, citing Office of the Public Advocate (Victoria) and Office of the Public Advocate (South Australia), Submission to the ALRC Discussion Paper.

[54] Quinn, 2010, 1.

[55] *Guardianship and Administration Act 2019* (Vic) s 9(1)(e).

[56] *Guardianship and Administration Act 2019* (Vic) s 15(b).

this role. OPA sees the NDIS, with its central tenet of promoting choice and control, as a potential driver to increasing the accessibility and availability of decision-making supports, but this has not yet materialised.

9.2. Supported decision making and the NDIS

OPA observes an overreliance by the NDIA on substitute decision-making as a means for supporting participants in completing administrative requirements of the NDIS access and planning process (e.g. signing an Access Request Form or service agreement), even when there may be informal supports available and better placed to intervene.

Supported decision-making is not yet a service that is explicitly funded or available for purchase in the NDIS market (although it can arguably come through other supports). There have been some attempts that should not go unnoticed. In 2016, OPA and the Victorian Advocacy League for Individuals with Disability (VALID) undertook a joint project called the OVAL Project. The project involved matching volunteers trained in the practice of support for decisions making with NDIS participants who wanted and needed this type of support. In 2018, the National Disability Advocacy Program (NDAP) and the Commonwealth Department of Social Services launched the Decision Support Pilot Project. The Decision Support Pilot Project provides advocacy and decision-making support for potential and current NDIS participants who have limited decision-making capacity and no other appropriate informal (i.e. family, friend, significant other) or formal (i.e. guardian) decision-making supports.[57] In Victoria, the pilot is led by Leadership Plus who have had great success and are now operating at capacity with a wait list.

These projects, and their overwhelming uptake, demonstrate the power of supported decision-making to support people with disability to build their capacity to make decisions and determine their own lives. They also demonstrate that the community, despite the presence of exclusionary attitudes among some members, is a rich resource for supporting isolated people with disability. When given the opportunity to develop a voluntary relationship with a local person with cognitive disability wanting support with their decision-making, community members of different backgrounds responded generously.

Indeed, an independent university-led evaluation of the OVAL Project found that both parties highly valued the relationship. The decision-making support provided by the volunteers led to significant changes in the lives of the persons with disability, including changes to support plans, service providers, life stages (e.g. getting engaged), finding employment and commencing education. The persons with disability highly valued having someone who was outside the service sector in their life. They perceived volunteers were on their side and would not tell them what to do.[58]

The final report recommends that proposals for future volunteer-based support for decision-making initiatives should be encouraged and, where appropriate, funded through the Independent Linkages and Capacity Building (ILC) framework. OPA encourages the Royal Commission to engage with the report's findings and recommendations and notes the provision of supported decision-making is also important for decisions that relate to matters outside of the NDIS.

Access to supported decision-making is an entitlement. A further key issue remains for those people who require support to request supported decision-making or to even know it is an option. Strategies are required to promote the entitlement to supported decision-making and funding is needed to help people—particularly people with significant cognitive impairment—to obtain the support needed to seek it out. What of people who do not have

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[57] http://leadershipplus.com/advocacy/

[58] OVAL Project Team, 2016. *The OVAL project*

capacity to consent to supported decision-making, but where advocacy (where it is available) is not enough and substitute decision-making is not required?

Even though Victoria in particular has made the important step of recognising supported decision-making in various key legislation, it remains that not all people who could benefit from supported decision-making can access it.

OPA makes the following recommendations to that end.

Recommendation 5
Governments should strengthen human rights protections to make 'choice and control' more meaningful by funding a range of supported decision-making initiatives. This can be achieved by making it possible for NDIS participants to purchase such supports through their NDIS plan.

Recommendation 6
The Australian Government should implement the Recommendations of the Australian Law Reform Commission in its 2014 report *Equality, Capacity and Disability in Commonwealth Laws*.