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

Health care for people with cognitive disability

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Abbreviations

AHPRA	Australian Health Practitioner Regulation Agency
ARF	Access Request Form
COAG	Council of Australian Governments
CRPD	United Nations *Convention on the Rights of Persons with Disabilities*
DHHS	Department of Health and Human Services
ECHR	European Court of Human Rights
HLO	Health Liaison Officer
MTPD Act	*Medical Treatment Planning and Decisions Act 2016* (Vic)
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
OPA	Office of the Public Advocate
SDA	Specialist Disability Accommodation
SRS	Supported Residential Services
VCAT	Victorian Civil and Administrative Tribunal

Recommendations

Recommendation 1

The National Disability Insurance Agency should consider adding professional supported decision-making services as a line item that could be funded in individual participant plans.

Recommendation 2

The National Disability Insurance Agency should continue funding volunteer support for decision-making programs and consider the feasibility of rolling out volunteer programs nationally.

Recommendation 3

The NDIS Quality and Safeguards Commission should, as part of their regular quality audits, audit compliance with medical treatment decision-making legislative obligations.

Recommendation 4

The Australian Health Practitioner Regulation Agency should ensure that all health practitioners are trained on the *Medical Treatment Planning and Decisions Act 2016* (Vic) and similar legislation in other jurisdictions.

In the Victorian context, the training should:

- adopt a human rights framework
- describe the supported decision-making paradigm and how it applies in a health care setting
- provide the skills necessary for health practitioners to assess decision-making capacity in line with legislation and the supported decision-making paradigm
- explain the legislated course of action to follow in making medical treatment decisions when a patient lacks decision-making capacity.

Recommendation 5

The Council of Australian Governments (COAG) Health Council should urgently develop and implement a legislated safeguarding framework to oversee the use of restrictive practices by health practitioners in hospital settings.

Recommendation 6

The Australian Health Practitioner Regulation Agency should ensure that ongoing professional development opportunities are available on the lawful use of restrictive practices. In Victoria, this would include compliance with the *Charter of Human Rights and Responsibilities Act 2006* (Vic).

Recommendation 7

The National Disability Insurance Agency should implement a policy that all participants with complex communication needs:

- receive a communication assessment by a speech pathologist every two years
- have a detailed implementation plan to guide staff in facilitating client participation and autonomy in decision-making.

Recommendation 8

Primary Health Networks should implement a policy that all patients who present to health services with complex communication needs are referred to an independent advocate where there is no known and available support person.

Recommendation 9

The Australian Health Practitioner Regulation Agency should ensure that all health practitioners receive training to enhance their capacity to provide accessible and high-quality health care to people with cognitive disability. The training should instruct practitioners how to:

- actively promote the needs and human rights of people with disability including issues of consent, right to treatment, and capacity
- support people with cognitive disability during pre-admission and discharge planning
- provide communication advice
- liaise with general practitioners, community health and social care teams
- identify required supports, including NDIS supports
- advise and work with the families and carers of people with disability.

Recommendation 10

The National Disability Insurance Agency's administrative processes, including at the point of access to the scheme, should be sufficiently flexible to enable it to give full effect to its legislative obligation to ensure that participants and potential participants are provided with the support to make and implement their own decisions.

1. Introduction

1.1. About the Office of the Public Advocate

The Office of the Public Advocate (OPA) is a Victorian statutory body, independent of government and government services. It 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. Last year, OPA was involved in 1,823 guardianship matters (978 of which were new), 404 investigations, and 258 cases requiring advocacy.[1] Among OPA's new guardianship clients, forty-nine per cent were over 65 years of age. Approximately half (58 per cent) of eligible guardianship clients were National Disability Insurance Scheme (NDIS) participants.[2] Of all guardianship matters allocated in 2018-19, 263 included powers to make decisions related to medical treatment.

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. Last year, 18 investigations (or 4.8 per cent of investigations) were referred to OPA regarding medical treatment.

The Public Advocate also has a decision-making role under the *Medical Treatment Planning and Decisions Act 2016* (Vic). OPA's medical treatment decisions team responds to requests for the Public Advocate to make decisions under that Act and last year, it responded to 466 applications for a medical treatment decision.

Under the *Guardianship and Administration Act 2019* (Vic),[3] OPA is required to arrange, coordinate, and promote informed public awareness and understanding about substitute decision-making laws and any other legislation affecting persons with disability. Last year, OPA's advice service took 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 decision-making.

OPA is supported by more than 700 volunteers across four volunteer programs: the Community Visitors Program, the Community Guardianship Program, the Independent Third Person Program (ITP Program) and the Corrections Independent Support Officer (CISO) 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

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[1] Office of the Public Advocate (Vic), *Annual Report 2018-19*, 9.
[2] OPA internal program data.
[3] The *Guardianship and Administration Act 2019* (Vic) commenced on 1 March 2020. It replaces the *Guardianship and Administration Act 1986* (Vic).

residents are not subject to abuse, neglect or exploitation. Community Visitors report annually to the Victorian Parliament on the quality and safety of the services they visit.

More than 400 Community Visitors visit across three streams: disability services, supported residential services, and mental health services. Last year, Community Visitors made 5,527 statutory visits across all three streams.[4]

1.2. OPA's engagement with the Royal Commission

OPA welcomes the ongoing opportunities to contribute to the Royal Commission into violence, abuse, neglect, and exploitation of people with disability (Royal Commission).

The Public Advocate, along with two Community Visitors, appeared as witnesses at the Royal Commission's December 2019 hearing into group homes. In November 2019, OPA released *I'm too scared to come out of my room* as its submission to the Royal Commission *Group Homes* Issues Paper.

This submission responds to the Royal Commission's Issues Paper on *Health care for people with cognitive disability*. It is based on OPA's experience in supporting people with cognitive impairment, and specifically on observations gathered from OPA's Advocate Guardian Program, medical treatment decisions team, and Community Visitors Program.

Using a human rights approach, this submission explores the following barriers that people with cognitive disability experience with the health system, all of which are identified in the Issues Paper:

- barriers faced by people with cognitive disability in making or being supported to make medical treatment decision-making
- the use of restrictive practices by health practitioners and other service providers and the safeguarding gap that remains in the absence of a comprehensive framework regulating deprivations of liberty
- discriminatory attitudes towards people with cognitive disability and their repercussions in the delivery of health care services
- delays in hospital discharge occasioned by systemic issues, such as shortages in accommodation.

Four case stories are presented to illustrate the impact of these issues on people with cognitive impairment. All case stories use pseudonyms and have been de-identified for the purposes of maintaining confidentiality.

1.3. Case story: Charlotte

Community Visitors and OPA advocated for a young woman, Charlotte, who lived in a group home and died from sepsis following a lengthy and yet untreated infection. The circumstances of her death were investigated by the coroner.

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

Charlotte was non-verbal but could communicate her needs quite effectively through facial expressions and body movements. Her family had, for the most part, relinquished her care to the group home where she had been living for many years and received occasional visits from her mother.

Community Visitors had long-standing concerns about the overall quality of services at this group home. More specifically, in relation to Charlotte, Community Visitors noticed her reduced mobility, increased risks of falls, soiled bedsheets, inadequate feeding and subsequent sudden weight loss. At the time of her death, she was severely emaciated but the reasons for weight loss were not investigated and remained unexplained.

There were also serious concerns related to the healthcare provided to Charlotte. She had experienced two previous instances of the same infection in childhood, which her paediatrician had fully documented and marked as a risk factor in a handover to Charlotte's adult general practitioner, and yet this medical history did not seem to influence decisions made by health practitioners. Staff in the group home requested speech pathology and occupational therapy assessments following the decline in Charlotte's overall health, but the assessments had been delayed, preventing the timely implementation of needed supports during the six months preceding her death.

The coronial inquest concluded that the care and management provided to Charlotte were reasonable in the circumstances, which sits at odds with the concerns raised by OPA during the investigation. OPA contends that Charlotte presented to hospital with severe health issues yet was prematurely discharged, leading to a worse and avoidable outcome. Charlotte had complex communication needs and no independent advocate to support her. Furthermore, the treating team assumed Charlotte's mother was the appointed attorney and therefore failed to seek consent for the proposed treatment from the Public Advocate as was required under section 42K of the *Guardianship and Administration Act 1986* (Vic) in effect at that time.

2. Medical treatment decision-making

The Issues Paper draws on Article 25 of the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) that persons with disabilities have the right to enjoy the highest attainable standard of health without discrimination on the basis of disability. The right to control one's own health and body is one of many entitlements and freedoms that are contained within, and help to realise, the right to be healthy.

Article 12 of the CRPD – equal recognition before the law – is also relevant. It recognises that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. It further articulates that States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. In the context of health care, this means people with disability have a right to make decisions about their health to the greatest extent possible, and to receive the supports they may need to so.

These two foundational rights – to enjoy good health and to control one's health – are enshrined within the *Australian Charter of Healthcare Rights*. The Charter is clear that all patients have a right to be included in decisions and choices about their health care and that patients should receive open, timely, and appropriate communication about their health care in a way they can understand.[5] In Victoria, health services are also bound by the *Charter of Human Rights and Responsibilities Act 2006* (Vic).

OPA appreciates that legislation relating to medical treatment planning and decision-making more broadly sit within the jurisdiction of States and Territories. Victoria is often at the forefront of reforms relating to the rights of people with disability.

Indeed, in 2018, OPA welcomed landmark legislative reform with the commencement Victorian *Medical Treatment Planning and Decisions Act 2016* (Vic) (MTPD Act). The MTPD Act is an important human right development because it gives effect to Article 12 of the CRPD by legislating supported decision-making in relation to medical treatment decisions. The MTPD Act, like other Victorian legislation, represents a significant and noteworthy advancement of the rights of people with disability, and particularly people with cognitive disability, in Victoria. OPA strongly advocates for similar legislation to be replicated across Australia.

2.1. Supported decision-making in health care settings

Supported decision-making is the provision of decision-making supports that enable persons with cognitive disability 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 substituted decision-making.

CEO of the Centre for Intellectual Disability, Justine O'Neil, explained supported decision-making in the following way when she appeared as a witness before the Royal Commission:

> Supported decision-making is recognising adults' rights and people's rights to make decisions for themselves and trying to work out what kinds of supports do you build in to really stretch out the number of people who can make their own decisions or, at the very least, participate to the greatest extent possible.[6]

Supported decision-making starts with the presumption that all adults have decision-making capacity unless there is evidence to the contrary.[7] The criteria for assessing a person's decision-making capacity are contained in various legislations, depending on the nature of the decision at hand. In Victoria, section 4(1) of the MTPD Act sets out four criteria that a health practitioner must initially apply in determining whether a person has capacity to make decisions related to medical treatment:

> A person has decision-making capacity to make a decision to which this Act applies if the person is able to do the following-
>
> (a) understand the information relevant to the decision and the effect of the decision;
>
> (b) retain that information to the extent necessary to make the decision;

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[5] https://www2.health.vic.gov.au/about/participation-and-communication/australian-charter-healthcare-rights/about-the-charter

[6] Transcript of Proceedings, (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Tuesday 18 February 2020) 30.

[7] *Medical Treatment Planning and Decisions Act 2016* (Vic) s4(2).

(c) use or weigh that information as part of the process of making the decision;
(d) communication the decision and the person's views and needs as to the decision in some way, including by speech, gestures or other means.

A fundamental principle of the supported decision-making framework is that a person is considered to have decision-making capacity if they can make decisions when provided with practicable and appropriate support. This is consistent with Article 12 of the CRPD and in Victoria, is contained in section 4(4)(d) of the MTPD Act. Examples of decision-making supports that can be provided in a health care setting include providing additional time, using modified language or visual aids such as pictures or video, and having someone help by assisting to communicate a decision.

Supported decision-making is specifically enabled in four Acts in Victoria; OPA's guide, *Side by Side,* describes the different legally recognised roles for decision-supporters. This submission focuses on the MTPD Act, but it is worth mentioning that the *Mental Health Act 2014* (Vic) promotes supported decision-making, for instance, by allowing consumers to nominate a person to make medical treatment decisions related to mental illness on their behalf or to provide them with the supports necessary to decision-making. A person can also make an advance statement and advance care directives to document their preferences and values for any treatment for mental illness.

OPA has a number of resources on supported decision-making and, most recently, has partnered with Reinforce to produce two print resources for adults with intellectual disability and health practitioners to promote supported decision-making in a health care setting. *Your right to make your own medical decisions*[8] is an Easy Read resource providing tools for people with intellectual disability on how they can be supported to make their own medical decisions. *The right of people to make their own medical decisions*[9] is the accompanying resource which provides information on the relevant laws in Victoria (i.e. the MTPD Act and the *Charter of Human Rights and Responsibilities Act 2006* (Vic)) and the related articles of the CRPD. It delivers practical information to health practitioners on how they can help to realise the right of their patients to make their own decisions about their medical treatment. The resource presents real stories demonstrating how supported decision-making can be applied in a health care setting.

Role of health practitioners

OPA questions whether Victorian health practitioners are fully aware of the supported decision-making paradigm contained within the MTPD Act when assessing the decision-making capacity of their patients.

OPA observes that health practitioners are still grappling with the move away from 'disability' to a determination of 'decision-making capacity' as the criteria for establishing the need for a medical treatment decision-maker. In OPA's experience, health practitioners are not yet sufficiently skilled in assessing decision-making capacity in accordance with section 4 of the MTPD Act, and thus do not yet appreciate the various ways in which they can, and must, support their patients to exercise their right to make decisions about their health.

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[8] https://www.publicadvocate.vic.gov.au/resources/fact-sheets/medical-decisions/645-your-right-to-make-your-own-medical-decisions-easy-read

[9] https://www.publicadvocate.vic.gov.au/resources/fact-sheets/medical-decisions/644-the-right-of-people-to-make-their-own-medical-decisions

More specifically, OPA questions whether health practitioners are effectively applying section 4(4)(d) of the MTPD Act to assess whether the person can make a decision when provided with appropriate and practicable support. The application of this provision will inevitably vary across different health settings. For example, acute health settings operate with significant and sometimes rigid time constraints, whereas family medicine practices can be more flexible. Nonetheless, efforts should be made to provide decision-making supports to patients on every occasion, and health practitioners are best placed to determine which supports are appropriate and practicable depending on the context.

Low compliance with the provisions of the MTPD Act may be due to supported decision-making only recently gaining recognition in medical treatment legislation. Policies and instructional materials for health practitioners are also lagging in incorporating the framework. For instance, the Medical Board of Australia's *Code of Conduct for doctors in Australia* is dated March 2014 and consequently, makes no reference to supported decision-making to the extent that it appears in the MTPD Act. Instead, the Code simply refers to 'shared decision-making' in the following way: "Making decisions about healthcare is the shared responsibility of the doctor and the patient. Patients may wish to involve their family, carer or others."[10] This outdated explanation fails to impart on practitioners their legal obligations to provide decision-making supports to patients when providing health care.

There is a pressing need for health practitioners and services to adapt their policies and practices to enable the full realisation of the legal right of patients to make their own decisions, and to be supported in doing so. Recommendation 4 addresses this.

Role of disability service providers

Disability service providers have obligations to ensure that the people to whom they owe a duty of care are supported to make their own decisions, including health and medical decisions. In the NDIS context, for instance, the NDIS Code of Conduct is clear that workers and providers must support people with disability to make decisions. The Code states:

Adults with disability should receive the support they need to make any decision. Adults with disability have the right to choose who does and who does not help them to make any given decision. Workers should work directly with the person with disability wherever possible. They should consult them about who, if anyone, they want to involve in decisions and discussions about their services and supports.[11]

Further, in the *NDIS Practice Standards*, under the standard of 'independent and informed choice', providers must demonstrate that:

> Active decision-making and individual choice is supported for each participant including the timely provision of information using the language, mode of communication and terms that the participant is most likely to understand.[12]

OPA appreciates that NDIS plan nominees can act as decision-making supporters, but some people with cognitive disability do not have natural or informal supporters to take on

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[10] Medical Board of Australia, *Good Medical Practice: A Code of Conduct for doctors in Australia* (March 2014) 6.

[11] NDIS Quality and Safeguards Commission, *The NDIS Code of Conduct: Guidance for Workers* (March 2019) 6-7.

[12] NDIS Quality and Safeguards Commission, *NDIS Practice Standards and Quality Indicators* (January 2020), 6.

the role of a plan nominee. OPA welcomes recent initiatives to provide decision-making supports to participants with limited informal supports in their life. The National Disability Insurance Agency (NDIA) has funded volunteer models of supported decision-making (namely the OVAL and Choice Mentor Programs). A more recent initiative is the Decision Support Pilot Project, a partnership between the National Disability Advocacy Program (NDAP) and the Australian Department of Social Services (DSS). The Decision Support Pilot 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.[13] In Victoria, the pilot is led by Leadership Plus who have had great success and are now operating at capacity with a wait list.

The pilot is an important initiative, but it is limited to supporting participants with NDIS-related decisions. Individuals with cognitive impairment need supports to make decisions in areas of their life, such as medical treatment, that lie outside NDIS plan decisions. The NDIS is an opportunity to enable and facilitate greater access to decision-making supports.

OPA advocates for decision-making supports to be available as NDIS-funded supports, including to support people with disability in making decisions related to medical treatment. OPA makes the following recommendations, encouraging the NDIA to consider models of both volunteer and professional decision-making supporters.

Recommendation 1

The National Disability Insurance Agency should consider adding professional supported decision-making services as a line item that could be funded in individual participant plans.

Recommendation 2

The National Disability Insurance Agency should continue funding volunteer support for decision-making programs and consider the feasibility of rolling out volunteer programs nationally.

2.2. Substitute decision-making in health care settings

People with cognitive impairment who lack decision-making capacity in relation to medical treatment decisions regularly receive medical treatment. OPA holds concerns about who, if anyone, is making medical treatment decisions on their behalf and how they are being made.

In Victoria, the MTPD Act provides that if a patient does not have decision-making capacity to make medical treatment decisions, a substitute decision-maker (i.e. the medical treatment decision-maker) must make the decision on their behalf. The medical treatment decision-maker is either the appointed medical treatment decision-maker or the default person according to the statutory hierarchy prescribed by section 55 of the Act. If there is no substitute medical treatment decision-maker, health practitioners must then, as a last resort, make a request to the Public Advocate to make a medical treatment decision where

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

the relevant decision is in relation to ‘significant medical treatment’ as defined under the Act.[14] (The requirements differ for routine or emergency medical treatment, which can be provided without consent in the absence of a medical treatment decision-maker). This circumvents the previous requirement to make an application to the Victorian Civil and Administrative Tribunal (VCAT) for the appointment of a guardian to make the decision, which is a lengthier and overly restrictive process in this context.

The MTPD Act is more closely aligned with Article 12 of the CRPD: it moves away from a ‘best interests’ model of substitute decision-making to a ‘substituted judgment’ approach. This is a very positive and welcome development. Substituted judgment requires any substitute decision-maker to uphold the ‘values and preferences’ of a person when making decisions on their behalf. Therefore, when OPA is requested to make a medical treatment decision, it seeks to ascertain the affected person’s values and preferences, either by direct contact with the person wherever possible or through consultation with family or other close associates. Decisions are thoroughly documented and provided to health practitioners to place on the patient’s medical record to give a clear and more detailed account of how the decision was made.

Role of health practitioners

OPA observes a very low level of understanding of, and compliance with, relevant legislative requirements for substitute decision-making by some health practitioners in Victoria, and suspects that these issues are widespread. OPA data shows that, of the 466 applications received last year for the Public Advocate to make a decision relating to significant medical treatment, 92.3 per cent were from public health services.[15] The remaining were from general practitioners, specialist medical services and private hospitals, evidencing low compliance within these settings.

Under the MTPD Act, some medication, when prescribed to a patient who lacks decision-making capacity, qualifies as ‘significant medical treatment’. Under these circumstances, a health practitioner must seek consent for the treatment from a substitute decision-maker, regardless of the setting in which the treatment is provided.

Concerningly, in the two years since the commencement of the MTPD Act, OPA has received less than 20 requests a year for a medical treatment decision in respect of prescribed medication. Anecdotally, OPA’s medical treatment decisions team has noticed practitioners have developed some awareness, albeit minimal, of the requirement to seek consent for the prescription of anti-psychotic medication. More substantial gaps in knowledge and compliance persist for all other types of prescribed medication, including those used to treat chronic and/or physical conditions like diabetes or epilepsy, medication prescribed for pain or treatment of infections, and anti-coagulants.

There is an obvious need for health practitioners to receive comprehensive training on this and other aspects of the legislation. While OPA does provide some training on the MTPD Act, it focuses on supported and substitute decision-making and the role of the Public Advocate under the Act. More could be done from within the health sector. In addition to training and education, legislative requirements relating to medical treatment decision-making should be made explicit. Recommendation 4 goes to this point.

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[14] *Medical Treatment Planning and Decisions Act 2016* (Vic) s63.

[15] Office of the Public Advocate (Vic), *Annual Report 2018-19*, 28.

Role of disability service providers

OPA is concerned that, similar to health practitioners, Victorian disability service providers are not complying with laws concerning medical treatment decision-making in relation to residents or clients who lack decision-making capacity. It is alarming that since the commencement of the MTPD Act in March 2018, OPA has only received a handful of applications from disability service providers to make a decision relating to significant medical treatment.

Some disability service providers employ health practitioners to deliver health care directly within their services. As well, workers in disability services are typically the ones identifying when there is a need for health care to be provided to the individuals they are supporting. They play a key role by, for example, accompanying clients to their medical appointments and providing important information to treating practitioners on their clients' daily living arrangements and behaviours. Perhaps most importantly, service providers will usually know who in the client's life, if anyone, could act as a medical treatment decision-maker.

The *NDIS Code of Conduct* states that service providers and their staff must "act with respect for individual rights to freedom of expression, self-determination and decision-making in accordance with applicable laws and conventions."[16]

The *NDIS Practice Standards* provide additional guidance on how a provider might enact this obligation, for example under the standard of 'governance and operational management', providers must demonstrate the following indicator:

> A defined structure is implemented by the governing body to meet a governing body's financial, legislative, regulatory and contractual responsibilities, and to monitor and respond to quality and safeguarding matters associated with delivering supports to participants.[17]

Taken together and applied in the context of medical treatment decision-making, these obligations could act to ensure an authorised decision-maker is sought to make medical treatment decisions for NDIS participants if they are unable to make that decision themselves. The NDIS Quality and Safeguards Commission could conduct an audit on this area of practice, using its powers and functions articulated under Part 2 of the *National Disability Insurance Scheme Act 2013* (Cth).

Recommendation 3

The NDIS Quality and Safeguards Commission should, as part of their regular quality audits, audit compliance with medical treatment decision-making legislative obligations.

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[16] NDIS Quality and Safeguards Commission, *The NDIS Code of Conduct: Guidance for Workers* (March 2019) 5.

[17] NDIS Quality and Safeguards Commission, *NDIS Practice Standards and Quality Indicators, version 3*, (January 2020) 7.

2.3. Overall compliance with the MTPD Act

The MTPD Act commenced two years ago on 12 March 2018 but there continues to be indications that the legislation is not yet well-understood, or complied with, by health practitioners. The following observations are in addition to concerns raised above:

- Based on population distribution, OPA expected to see more applications from rural health networks but requests for decisions from practitioners in rural and regional Victoria are sparse.
- There is an underrepresentation of requests for medical treatment decisions for the administration of prescribed medication, as described in section 2.2 of this submission.
- There is a surprisingly high number of forms submitted to OPA by health services for medical treatment decisions related to emergency treatments which do not require consent, pointing to another gap in practitioners' understanding of the legislation.
- Because hospitals are 24/7 services, practitioners often have the expectation that a request for a medical treatment decision by OPA can also be made 24/7 and responded to with very short turnaround times (e.g. submitting forms on the day of a proposed treatment). This is not possible due to the requirements that the medical treatment decision-maker take the time to establish and be guided by the preferences and values of the person.

OPA suspects some of these issues will be resolved as practitioners become more familiar with the principles, use, and application of the MTPD Act. OPA continues to develop and tailor education activities on the MTPD Act for health care practitioners and the community more broadly. In addition to in-person training, online and print resources are available that translate the provisions of the MTPD Act into practice. For example, health practitioners can use a flow chart and accompanying mobile device app to determine whether an adult patient can consent to treatment.[18]

In its 2019 outcomes report on Australia, the United Nations Committee on the Rights of Persons with Disabilities made the following recommendations:

- All health care services should be based on a non-discriminatory, human rights model to disability, and on the basis of free and informed consent of the person concerned prior to any medical treatment.
- Health care practitioners receive training on the human rights model of disability to enhance their capacity to provide accessible, quality health care to persons with disabilities.[19]

The Australian Health Practitioner Regulation Agency (AHPRA) is the body that regulates the health care workforce. In its *National Registration and Accreditation Scheme Strategy 2015-20*, it lists as an outcome that "registered health practitioners are suitably trained and qualified to practice in a competent and ethical manner."[20] OPA therefore makes the following recommendation.

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[18] https://www.publicadvocate.vic.gov.au/resources/flowcharts/341-can-your-adult-patient-consent-flowchart

[19] United Nations Committee on the Rights of Persons with Disabilities, *Concluding Observations: UN Report on Australia's Review of the Convention on the Rights of Persons with Disability (CRPD)* (24 September 2019) 12.

[20] https://www.ahpra.gov.au/About-AHPRA/What-We-Do/NRAS-Strategy-2015-2020.aspx

Recommendation 4

The Australian Health Practitioner Regulation Agency should ensure that all health practitioners are trained on the *Medical Treatment Planning and Decisions Act 2016* (Vic) and similar legislation in other jurisdictions.

In the Victorian context, the training should:
- **adopt a human rights framework**
- **describe the supported decision-making paradigm and how it applies in a health care setting**
- **provide the skills necessary for health practitioners to assess decision-making capacity in line with legislation and the supported decision-making paradigm**
- **explain the legislated course of action to follow in making medical treatment decisions when a patient lacks decision-making capacity.**

3. Restrictive practices

3.1. Case story: Oliver

Oliver is a young man with an intellectual disability and Autism Spectrum Disorder. He is non-verbal and has no use of sign language or other consistent body language cues; when he does not want someone or something, he will use his hands to push them or the object away.

Oliver was admitted to hospital for treatment of significant physical injuries sustained in an accident. Community Visitors found Oliver in rehabilitation following treatment for his injuries, naked and restrained to the bed by 4-point shackles (i.e. ankles and wrists). They made a notification to the Public Advocate. OPA undertook an investigation and subsequently became involved as a guardian and an advocate.

OPA discovered that restrictive practices had been used on Oliver for many months and that he was subject to three restraint mechanisms that affected his freedom: psychotropic medication to quieten him, shackles to physically restrain his movements, and containment to prevent him from leaving the unit.

As a result, his level of agitation steadily increased with behaviours related to rectal digging, taking off his clothes and wanting to be naked, defecating on the floor, and at times being very physically agitated. He was left to urinate and defecate in his bed as hospital staff were not permitted to remove his shackles for him to access the toilet.

Initially, Oliver was unable to comply with medical advice so there was a clinical need for the use of physical restraints to enable Oliver's injuries to heal. Once Oliver's injuries had healed, the treating team continued with these measures because of concerns for staff safety. The hospital also advised that Oliver's family had approved the use of restrictive practices, however it is unclear under what authority they could do so.

A number of months passed until the Department of Health and Human Services (DHHS) agreed to fund behaviour specialists to work with Oliver while in hospital.[21] The behaviour specialists worked with Oliver for up to 12 hours a day, during which time it was possible to remove the shackles to reduce his levels of agitation. While nursing staff were invited to remain in the room when support workers were present in order for them to learn engagement strategies, they instead observed from outside the room.

Similarly, Oliver's restraints were also removed when his family visited, yet Oliver's family found the hospital reluctant to let them educate staff on how to support their son. Further, the hospital refused to let his family take him out onto the hospital grounds with a wheelchair. When the disability workers or his parents were unavailable, Oliver remained under restraint for the entire day.

Oliver's mobility was compromised by his injuries to the extent that he could not walk, and there were concerns that this could be permanent. Despite this, Oliver was not provided physiotherapy or occupational therapy because staff were too scared to interact with him unless he was shackled.

It was many months after his initial admission to the hospital that DHHS offered Oliver suitable interim accommodation. He was eventually offered permanent shared supported accommodation where he now continues to reside.

3.2. Safeguarding deprivations of liberty

Many people with cognitive disabilities, mental illness and/or age-related disabilities are admitted to, and reside in, places like group homes, hospitals and aged care facilities where they are subject to very high levels of supervision and restrictions on their liberty. While some people are clearly unhappy with the restrictions, others who may appear to be complying with, or acquiescing to them may not be giving full, free and informed consent.

The use of restrictive practices[22] significantly infringes on a person's human and legal rights and their use should be justified and authorised in each instance. However, the legislative environment is incredibly complex in that the applicable safeguards surrounding the use of restrictive practices, if any, are tied to the setting where the restrictive practice is administered, as below.

- In hospitals, no legislated safeguards apply but the common-law doctrine of necessity can be used in an emergency. However, health practitioners have no obligation to report the circumstances in which they use restrictive practices or for how long.
- In Victorian disability services, either the *Disability Act 2006* (Vic) or the *National Disability Insurance Scheme Act 2013* (Cth) applies, depending on the service's funding source.
- In Victorian mental health services, the *Mental Health Act 2014* (Vic) applies.
- In aged care services, the *Aged Care Act 1997* (Cth) applies.

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[21] This case story pre-dates the NDIS, which explains the involvement of the DHHS.

[22] OPA adopts the language and definitions from the *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector*. A 'restrictive practice' is defined as any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with disability, with the primary purpose of protecting the person or others from harm. According to this definition, restrictive practices include seclusion, chemical restraint, mechanical restraint, physical restraint, and other practices, all of which are further defined in the Framework.

As health practitioners' transition from one sector to another, they must also, accordingly, adjust their practice framework, which includes different authorisation and reporting requirements. The lack of an overarching framework surrounding the use of restrictive practices, in combination with varying requirements across different laws, results in them being used in an inconsistent, unpredictable, arbitrary, and, therefore, likely an unlawful manner. There are no clear criteria, standards or processes to govern them and OPA is seriously concerned that restrictive practices that are prescribed and administered by health practitioners can go unmonitored.

The Issues Papers enquires about attitudes and assumptions that may encourage or deter from the use of restrictive practices. OPA looks at each of the above safeguarding regimes in turn to highlight some of the existing gaps that may lead to increased use of restrictive practices on people with disability. Particularly, OPA brings the Royal Commission's attention to hospitals where restrictive practices are, comparatively, unregulated.

This section of the submission points to a real need to design an overarching framework regulating the use of restrictive practices and other types of deprivation of liberty in social care settings. In 2017, OPA wrote a discussion paper, *Designing a deprivation of liberty authorisation and regulation framework*, to lay out preliminary thinking and design of such a framework. The paper is provided as an appendix to this submission.

The discussion paper in its entirety raises important considerations, but OPA draws one key point here: alternatives to restrictive practices should always be sought when delivering supports to people with disability, and this is true across all social care settings. Person-centred supports should be designed in a way that promotes wellbeing, and safety, thus avoiding the need for restrictions on one's liberty. Sector-wide solutions are needed that encourage upskilling of staff, moving away from medical and institutional models of care, and strategies for creating services that enhance and promote human rights.

3.3. Hospital settings

OPA is alarmed about the lack of safeguards around the use of restrictive practices in hospital settings, despite common knowledge that they are routinely used in hospital emergency departments and in other inpatient settings. This is especially concerning when there is evidence that health services are not always skilled at supporting people with cognitive impairment, as is well illustrated in the case stories presented in this submission.

In Oliver's story, the hospital initially relied on the doctrine of necessity to justify their use of restrictive practices. The common-law doctrine of necessity may justify an action when:

(1) there is a necessity to act when it is not practicable to communicate with the assisted person and
(2) the action taken is such as a reasonable person would in all the circumstance take, acting in the best interest of the assisted person.[23]

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[23] *In Re F* [1990] 2 AC 1

However, the scope of the doctrine is uncertain in terms of the period of time for which it may apply without oversight and review, and whether it applies to actions that are necessary for the benefit of others (such as hospital staff).

The European Court of Human Rights (ECHR) decision in the Bournewood case[24] set limits on the continued use of the doctrine to detain a person in light of the European Convention for the Protection of Human Rights and Fundamental Freedoms (the European Convention). The ECHR found that the "absence of procedural safeguards fails to protect against arbitrary deprivations of liberty on grounds of necessity" and, consequently, to comply with the relevant provisions of the European Convention.

The European Convention contains provisions similar to section 21 (right to liberty and security of person) of the *Charter of Human Rights and Responsibilities Act 2006* (Vic) (Charter). Therefore, the Charter could arguably serve to limit the scope of application of the doctrine of necessity. The Charter requires that any limitation of a person's human rights be proportionate, necessary, justified, and reasonable in the circumstances. In particular, a person must not be deprived of their liberty except on grounds of, and in accordance with, procedures established by law.[25]

The application of restrictive practices on Oliver was not subject to any external oversight or review. Decisions were made by the treating team alone with no regulatory oversight, a state of affairs criticised by the EHCR in the Bournewood case. Sadly, Oliver is not an isolated case. OPA guardians continue to work with people with cognitive impairment who are subject to restrictive practices in hospitals on an ongoing basis where the justification for the practices is the safety of staff. The lack of formal legal authority is one part of the problem. In many cases, it is unclear whether such deprivations of liberty are substantively necessary or justifiable.

The doctrine of necessity is not sufficient to safeguard the human rights of hospital patients. There have been calls for the use of chemical or physical restraints on aged care residents in emergency settings to be reported through the Serious Incident Response Scheme to the Australian Commission on Safety and Quality in Health Care.[26] While this recommendation relates specifically to residents in the aged care sector, it proposes a potential oversight role for the Commission that could be expanded to include all hospital services.

Recommendation 5

The Council of Australian Governments (COAG) Health Council should urgently develop and implement a legislated safeguarding framework to oversee the use of restrictive practices by health practitioners in hospital settings.

Recommendation 6

The Australian Health Practitioner Regulation Agency should ensure that ongoing professional development opportunities are available on the lawful use of restrictive practices. In Victoria, this would include compliance with the *Charter of Human Rights and Responsibilities Act 2006* (Vic).

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[24] H.L. v the United Kingdom (Application 45508/99) 5 October 2004

[25] *Charter of Human Rights and Responsibilities Act 2006* (Vic) s21(3)

[26] Transcript of Proceedings, *Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019*. (Parliamentary Joint Committee on Human Rights, Tuesday 20 August 2019) 55.

3.4. Disability services

In the disability sector, the *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector* outlines key principles and core strategies to reduce the use of restrictive practices in disability services. The framework aligns with the *National Disability Insurance Scheme Act 2013* (Cth) and the *Disability Act 2006* (Vic) in Victoria.

Under these laws and policies, a restrictive practice must be approved within a behaviour support plan, which is lodged with, and subject to the oversight of, the Senior Practitioner. Accordingly, all disability workers should be aware of whether there is a behaviour support plan in place when they are supporting a person with disability. This includes having knowledge of the restrictive interventions that are authorised through that plan and being trained to implement any positive behaviour support strategies to prevent and reduce the use of restrictive practices.

In appearing before the Royal Commission, NDIS Quality and Safeguards Commissioner, Graeme Head, described behaviour support plans in the following way:

> The behaviour support plan ought to be the thing that contextualises what's really driving a person's behaviour, what's happening for a person. It should provide the underpinning insights for an individual about what their behaviour means, what to observe, and, therefore, how do you make sure that in any use of a restrictive practice that's understood rather than defaulting to some kind of restraint.[27]

Behaviour support plans are an essential safeguard as they articulate and encourage evidence-based alternatives to restrictive practices. However, restrictive practices can nonetheless be administered outside of what is authorised in a plan. When an unauthorised restrictive practice is administered, it must be reported to the Senior Practitioner (at the State or Commonwealth level, depending on the funding source of the service) and there is growing evidence showing that this is a common occurrence.

The NDIS Quality and Safeguards Commissioner shared staggering data with the Royal Commission showing 65,000 reported instances[28] of unauthorised restrictive practices, in the six months from July to December 2019. OPA stresses that, in each of these instances, a restrictive practice was administered to a person with disability, without appropriate positive behaviour strategies being in place to prevent their future use.

In the NDIS context, only registered providers can deliver behaviour supports and, consequently, administer authorised restrictive practices. However, this does not preclude unregistered workers (or providers) from administering unauthorised restrictive practices. All NDIS providers and workers must, under the NDIS Code of Conduct, contribute to the reduction and elimination of restrictive practices, however the Code provides little guidance on how to do so.

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[27] Transcript of Proceedings, (Royal Commission into violence, abuse, neglect and exploitation of people with disability, Thursday 27 February 2020) 800.

[28] Ibid.

OPA suspects many NDIS workers administer unauthorised restrictive practices but do not report them, either willingly or inadvertently. For unregistered workers, it may be that the NDIS Code of Conduct and worker orientation module are not sufficient to explain what constitutes a restrictive practice and when to report its use.

All NDIS workers and providers, regardless of their registration status, must conduct their work in accordance with the law, in addition to the NDIS Code of Conduct. Providers and their staff must be cognisant of their legal obligations, in addition to knowing the individual needs of their clients.

OPA encourages the NDIS Quality and Safeguards Commission to undertake education and training on restrictive practices for unregistered NDIS workers and providers, as part of the Commissioner's education functions under the *National Disability Insurance Scheme Act 2013* (Cth).[29]

3.5. Mental health services

In the mental health sector, safeguards relating to the use of seclusion and restraints are legislated in the *Mental Health Act 2014* (Vic), which regulates the use of seclusion (i.e. environmental restraint), bodily restraint (i.e. physical restraint), as well as the use of two types of significant treatment (i.e. electroconvulsive treatment and neurosurgery).

In comparison with other Australian jurisdictions, Victoria's mental health sector has the highest number of compulsory treatment orders and involuntary admissions.[30] The prevalence of the use of restrictive practices such as seclusion and restraint in Victorian mental health services is also high overall and specifically for services supporting patients with dual disability and/or challenging behaviours. This attests to an inability of staff within these services to effectively support clients with cognitive impairment. OPA and Community Visitors observe this firsthand; mental health services are often reluctant to admit consumers with these profiles, even within the two state-wide Transition Support Units (TSU) that are dedicated to consumers with dual disability.

OPA is concerned that the provisions in the Mental Health Act that serve to safeguard fundamental rights of consumers do not apply consistently or equally across all mental health settings.

Under the Mental Health Act, compulsory orders – whether for assessment or treatment – can only be used in public mental health services, meaning that private mental health services refer and transfer patients to public services if and when they require compulsory treatment. In theory, private mental health services do not have seclusion rooms and it is assumed that they do not use other types of restraints. In practice, it is difficult to know whether this is true, as there is no reporting or oversight within these services.

Furthermore, the jurisdiction of the monitoring bodies established in the legislation, namely the Chief Psychiatrist, the Mental Health Complaints Commissioner, and the Mental Health Tribunal, is limited to public mental health services.

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[29] *National Disability Insurance Scheme Act 2013* (Cth) s181E.

[30] Victorian Mental Illness Awareness Council, *Seclusion Report: Accessible information on seclusion in Victorian mental health services* (April 2019).

OPA has further concerns about the limits of the safeguards provided in the Mental Health Act as it applies to older people, as the legislated safeguards only apply to 'designated mental health services' as defined in the Act. Not all residential aged mental health services fit within the definition of acute aged mental health units. Residential aged mental health care facilities must comply with the *Aged Care Act 1997* (Cth), however, at the time of writing this submission, Commonwealth funded aged care services operate with limited requirements to report on the use of restrictive interventions (see below), creating a significant gap in the safeguarding of aged mental health consumers. As a result, any use of restrictive interventions in these settings is unsupervised.

OPA raised these concerns in its submission[31] to the Royal Commission into Victoria's mental health system where it made multiple recommendations in relation to the review of the *Mental Health Act 2014* (Vic). The review of the Act was scheduled for 2019 but has not yet been announced; it is likely the review will occur once the Royal Commission into Victoria's mental health system has completed its work.

In its interim report, the Royal Commission stated that "the rates of compulsory treatment and restrictive practices are of concern to the Commission and will be the subject of further consideration in 2020."[32] OPA continues to monitor any developments and hopes the Disability Royal Commission will consider the findings of the Royal Commission into Victoria's mental health system.

3.6. Aged care services

The Royal Commission into Aged Care Quality and Safety has shed light on the use of restrictive practices, and particularly chemical restraints, within aged care services where there are many people with cognitive disability.

The *Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019* (Cth) (Restraints Principles) came in to force on 1 July 2019 and sought to regulate the use of physical and chemical restraints by aged care providers. As of that date, aged care providers must report any use of physical restraint to the Aged Care Quality and Safety Commission.

OPA has grave concerns about the adequacy of the Restraints Principles to regulate the use of restrictive practices in this sector and raised those concerns with the Parliamentary Joint Committee on Human Rights. The Committee subsequently held an inquiry into the Restraints Principles. OPA made a written submission advocating for the disallowance of the Principles and the Public Advocate appeared before the Committee to provide evidence on this issue.[33]

The Committee ultimately determined not to disallow the Principles, but recommended amendments to clarify how the instrument interacts with state and territory laws. The Committee also recommended further extensive consultation with stakeholders to better regulate the use of restrictive practices in aged care facilities, including a requirement to

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[31] https://www.publicadvocate.vic.gov.au/resources/submissions/mental-health-1/681-submission-to-royal-commission-into-victorias-mental-health-system

[32] State of Victoria, Royal Commission into Victoria's Mental Health System, *Interim Report*, Parl Paper No. 87 (2018–19) 93.

[33] https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Human_Rights/QualityCareAmendment

exhaust other options first, obtain consent, improve oversight and report on the use of restrictive practices.[34] It is worth noting that, exceptionally, there was a dissenting report by the Australian Labor and Green Party Members recommending that the Principles be disallowed.[35] Importantly, there must be a review of the first 12 months of the operation of the Restraint Principles.

The subsequent *Quality of Care Amendment (Reviewing Restraints Principles) Principles 2019* (Cth) strengthen the regulation of restrictive practices but remain problematic. In relation to chemical restraints, the amended principles make it clear that they are only to be used as a last resort and refer to state and territory legislation governing consent for the use of chemical restraint. As for physical restraints, consent is to be sought from a representative, but the amended principles only indicate, rather than determine, who could act as a representative and also allow for a person to appoint themselves in this role. OPA's concerns are detailed in its submission to the review of the principles.

OPA made recommendations to both the Royal Commission into Aged Care Quality and Safety and the Parliamentary Joint Committee on Human Rights, as the appropriate authorities to provide direction on the regulation of restrictive practices in aged care services. OPA is closely monitoring the operation of the amended Restraint Principles and encourages the Disability Royal Commission to do the same and to consider investigating further into this area of practice.

3.7. Chemical restraints

Chemical restraints are an infringement on one's rights, most evidently the right to freedom of movement. Research shows that when used repeatedly, the administration of pharmaceuticals poses significant health risks. For instance, the use of antipsychotic drugs on older people with dementia is associated with a nearly doubled risk of death.[36]

In a submission to the Parliamentary Joint Committee on Human Rights inquiry into the *Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019* (Cth), Human Rights Watch submitted that:

> Use of restraints can amount to cruel, inhuman, or degrading treatment and any forced medical treatment violates the right to health under international human rights law (...) Medicines should only ever be used for therapeutic purposes and with the free and informed consent of the person receiving them.[37]

OPA endorses Human Rights Watch's position and has further concerns that, despite the significant infringement of rights occasioned by the use of chemical restraints, the extent of their use remains unknown and mostly unregulated.

By way of its role as the medical treatment decision-maker of last resort under the MTPD Act, OPA does, on rare occasions, become aware of the use of chemical restraints on people with cognitive disability. This occurs when health practitioners have misinterpreted the legislation and contacted the Public Advocate requesting a medical treatment decision

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[34] Parliamentary Joint Committee on Human Rights, *Inquiry report, Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019* (2019) 54.
[35] Ibid 57.
[36] Human Rights Watch, *Submission to the Parliamentary Joint Committee on Human Rights* (May 2019) 1.
[37] Ibid.

in respect of the administration of psychotropic medication for the sole purpose of addressing behaviours of concern. OPA, or indeed any other medical treatment decision-maker, cannot make decisions in these circumstances because the use of medication for restraint (i.e. non-therapeutic purposes) does not fall within the definition of medical treatment under Victorian legislation.

To prescribe medication squarely as chemical restraint to someone who lacks decision-making capacity is unlawful. It is critical that safeguards be put in place to oversee the misuse of medication in this way and that services seek to implement alternative strategies and responses.

3.7.1. Prescription vs administration of medication

The Issues Paper notes that the right to be healthy encompasses the right to control one's health and body. Because of the nature of their disability, many people with cognitive impairment rely on others to receive health care. A concrete example of this, and one that is common in residential services, is when a person with disability requires assistance with the administration of medication. While this may seem, at face value, as a procedural exchange in a person's day, it can quickly lead to an infringement on rights when medication is used as a chemical restraint.

There is an important distinction to be made between the health practitioner who prescribes a medication for the purpose of chemical restraint (or behaviour management) and the person who administers it. Under the MTPD Act, the prescriber is the one who must obtain consent from the patient or the authorised decision-maker for the administration of a pharmaceutical. If the medication is intended as a restraint and prescribed to a person who lacks decision-making capacity, there is no role for a substitute decision-maker.

While the person who administers medication does not hold the legal responsibility under the MTPD Act (or its equivalent in other jurisdictions) to ensure that the patient or their medical treatment decision-maker consents to the treatment, they do have an obligation relevant to the lawful administration of medication and the minimisation of the use of restraints. This is well articulated in the following quote by Chief Clinical Advisor to the Aged Care Quality and Safety Commission, Dr Melanie Wroth:

> The service is accountable for having effective oversight to minimise the use of restraints. So, irrespective of the role of the treating practitioner, there are obligations on providers to ensure that they are achieving both regulatory compliance with state and territory law and effective clinical governance to minimise the use of restraints.[38]

A disability support worker, for example, is well-placed to recognise and respond to the misuse of medication on a person with disability.

The person who administers a chemical restraint may not be medically trained (i.e. a disability support worker or a worker in an aged care facility), but they will nonetheless be called on to exercise some form of clinical judgment. This is most obvious when a medication is prescribed by a doctor as PRN (meaning 'as needed'), thereby giving the

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[38] Transcript of Proceedings, *Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019*. (Parliamentary Joint Committee on Human Rights, Tuesday 20 August 2019) 28.

person who administers it the full authority to determine when, how much, and how often a medication will be administered. So, while most workers in residential services do not have medical training, they are effectively enacting the decision to chemically restrain their clients, as explained by Dr Wroth below:

> Restraint, when it's used in a PRN fashion, which is when the prescriber says you can use it when necessary, that leaves the discretion to administer it with the provider. Sometimes that may be somebody who has very little understanding of the medication and restraint, and even what PRN means. It’s very clear that it's the provider's responsibility to make sure that anyone who's exercising the discretion understands the reason for its use and the situation in which it can be used, and adequately documents the response to it. That’s another area of quite high risk.[39]

Health practitioners prescribing medication have clear legislated obligations relating to medical treatment decision-making, but the commitment to minimise the use of restraints and to protect and defend the rights of people with disability is one that is shared between the person prescribing and the person administering medication.

4. Health care for people with cognitive disability

The Issues Paper recognises that people with cognitive disability in Australia experience worse health outcomes than the general population. Australian data shows that people with intellectual disability die, on average, almost 30 years earlier than the general population – and more often from preventable causes of death.[40]

OPA has long standing concerns that the rehabilitation and health care needs of people with cognitive impairment are neglected, and that their rights are commonly infringed upon, by measures taken by services to manage disability-related behaviours and risk. OPA and Community Visitors also observe many of the examples identified in the Issues Paper, such as diagnostic overshadowing and delayed or mistaken diagnoses, by both health professionals and other service providers who support people with cognitive disability.

In this section of the submission, OPA identifies practices within health and other services that point to discriminatory attitudes towards people with disability and result in inequitable access to health care.

4.1. Case story: Jerry

OPA was guardian for a man with intellectual disability and dementia who was non-verbal. Jerry was transferred quite successfully from a group home to an aged care facility when his care needs changed as a result of his age. Several months after his move, the guardian received advice that Jerry had been admitted to a hospital with a fever and ‘behaviours of concern’. The hospital reported aggressive behaviours, self-harming, and assault of nursing staff. The guardian was surprised by these behaviours as they were uncharacteristic of Jerry and had not been evident previously.

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[39] Ibid.

[40] Disability Services Commissioner (Vic), *A review of disability service provision to people who have died 2017-18* (2018) 19.

The facility advised that Jerry had not received any pain relief and that in response to aggressive behaviours, his GP had prescribed anti-psychotic medication, which had not reduced the behaviours. The hospital treated Jerry with antibiotics and reduced the dosage of anti-psychotic, but it took some time before they diagnosed him with a septic infection.

What was minimised by support staff as disability-related ‘behaviours of concern’ were Jerry’s attempt to communicate his pain to staff. The facility staff are now aware that if Jerry behaviours of concern re-appear then he should be checked for an underlying medical condition.

4.2. The role of disability (and other) services

Disability and other support workers play a central role in facilitating access to health care for the people they support. Frontline staff in residential services know residents well and thus are able to identify a change in circumstances or behaviours. In Jerry’s story, for instance, the guardian and the facility staff were attuned to an unusual change in behaviour. The outcome is dependent on the interpretation of staff and carers of nonverbal cues communicating pain or distress; Jerry’s support staff misinterpreted his outwardly behaviours and consequently overlooked what was a call for assistance, thereby delaying necessary health care.

Community Visitors frequently observe neglect by staff of the health care needs of people with disability in residential settings, for example by minimising symptoms. Last year, Community Visitors identified 155 issues related to healthcare in disability residential services. Commonly noted issues include confusion and delays around diagnosis and treatment of seriously ill residents. For example, Community Visitors reported a case in which there were delays in diagnosing a leg fracture and a serious hip infection that was initially diagnosed as a urinary tract infection. Errors in the administration of medication are also frequently reported. In some instances, these issues result in the need for further medical treatment or even hospitalisation.

Similar issues arise in Supported Residential Services (SRS), which are privately operated residences in Victoria that provide accommodation and support for individuals who need help with everyday activities. Many people with disability reside in SRS, with mental illness and intellectual disability being the two most common types of disability. In pension-level SRS, which charge lower fees, a great proportion of residents have complex health needs, in addition to being adversely affected by poverty and lacking access to health services and prevention initiatives. Last year, Community Visitors reported 104 issues related to healthcare in SRS, the second highest documented issue category. Unexpected and premature deaths in pension-level SRS, including some related to drug overdose, are high in comparison with pension-plus SRS. For example, Community Visitors reported about an SRS resident who was unwell and slurring his speech yet was refused an ambulance on two occasions. On the third call to emergency services, he was taken by ambulance to a hospital where he later passed away.

OPA is aware, by way of its guardianship functions, that similar attitudes are present in aged care services, as illustrated in Jerry’s story, and raised in OPA’s submission to the Royal Commission into Aged Care Quality and Safety.[41]

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[41] https://www.publicadvocate.vic.gov.au/resources/submissions/royal-commission-into-aged-care-quality-and-safety/635-aged-care-submission-2017-word

4.3. Communication supports

At its Sydney hearings, the Royal Commission heard from witnesses that individuals who require communication supports face significant challenges in receiving health care. OPA and Community Visitors know, and are concerned, that some people with severe cognitive impairment have little to no informal supports to assist or advocate on their behalf. For some, the disability or aged care service provider can be the only support that is available. It is crucial for services to ensure all necessary assessments and support plans are kept up-to-date and shared with health care services, but this is not yet best practice.

The Royal Commission is aware of the recent review commissioned by the NDIS Quality and Safeguards Commission investigating the deaths of people with disability in receipt of specialist disability services from 2013 to 2019. The review found that, in Victoria, 38 per cent of individuals who required a communication plan did not have one on record. In other states, many persons with disability had an identified need for communication supports yet their support plan provided no details as to what they should be.[42] The review concludes that the basic right of people to be provided with supported communication adjustments is not always met and this can significantly impact on the delivery of timely and necessary health care.

Recommendation 7

The National Disability Insurance Agency should implement a policy that all participants with complex communication needs:

- **receive a communication assessment by a speech pathologist every two years**
- **have a detailed implementation plan to guide staff in facilitating client participation and autonomy in decision-making.**

Recommendation 8

Primary Health Networks should implement a policy that all patients who present to health services with complex communication needs are referred to an independent advocate, where there is no known and available support person.

4.4. Case story: Ruby

OPA is guardian for Ruby, an NDIS participant with complex needs and 'behaviours of concern' who was admitted to hospital. The hospital, when faced with the inability of their staff to respond to some of her behaviours, used physical restraints (i.e. wrists tied to the bed) to mitigate the risks that Ruby's behaviours imposed on their staff and on other patients. Ruby was physically restrained in this way for many months.

At the time of her admission to hospital, Ruby had an NDIS plan that included positive behaviour supports. The NDIS-funded behaviour supports could continue supporting her while she was in hospital; the behaviour specialists were present sometimes for 12 hours per day. During this time, they endeavoured to upskill hospital staff by coaching them on de-escalation techniques that could be used in place of restraints but were met with

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[42] Salomon C & Trollor J (2019). *A scoping review of causes and contributors to deaths of people with disability in Australia*, 51.

reluctance. The hospital staff considered that the NDIS supports served that very purpose, thus absolving the hospital of their responsibility to respond to disability-related needs.

4.5. Disability supports in hospital

OPA and Community Visitors observe that mainstream health services are often ill-equipped to support clients with cognitive impairment, particularly when patients present with behaviours that seem difficult to manage. Discriminatory attitudes prevail, leading to inequities in service delivery and, ultimately, poor health outcomes.

Oliver's story illustrates the inability of some hospital staff to provide health care for a person with a cognitive impairment. Increasingly, hospitals and other services are met with competing obligations to provide health care to patients with complex needs, all the while maintaining a safe workplace for staff. Too often, the person with a disability is the one who suffers by having their human rights infringed on. In Oliver's story, as in many others, externally sourced disability workers were required to support the hospital in delivering care. The NDIS has, in some ways, alleviated the pressure placed on hospitals to support patients with cognitive impairment.

By way of its guardianship functions, OPA is often involved in disputes between the NDIS and the health care systems to determine which is responsible for supporting people with disability who are in hospital, and in which way. The *Council of Australian Governments Principles to determine the responsibilities of the NDIS and other service systems* (COAG Principles) provide direction on the funding responsibilities of each system. One of the COAG Principles in relation to the health system specifies that:

> Any funding in a person's [NDIS] package would continue for supports for people with complex communication needs or challenging behaviours while accessing health services, including hospitals and inpatient facilities.[43]

In OPA's experience, this and other COAG Principles are mostly enacted. In recent years, the NDIA has become more flexible in allowing NDIS-funded supports to be provided in hospital settings, a welcome development. It also helps that familiarity with the scheme has improved, as it is becoming increasingly common for individuals with cognitive impairment to have an NDIS plan in place on entering hospital.

In line with the COAG Principles, NDIS-funded services can and are provided for NDIS participants who are in a hospital setting. The implementation of the COAG Principles has in some ways exposed deeply rooted discriminatory attitudes that persist within the health sector.

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[43] Council of Australian Governments *COAG Principles to determine the responsibilities of the NDIS and other service systems* (November 2015).

The first of six high-level and general COAG Principles for the health system reads as follows:

> Commonwealth and State and Territory health systems have a commitment to improve health outcomes for all Australians by providing access to quality health services based on their needs consistent with the requirements of the National Healthcare Agreement and other national agreements and in line with reasonable adjustment requirements (as required under the Commonwealth Disability Discrimination Act or similar legislation in jurisdictions).[44]

Yet, OPA see people with cognitive disability being denied safe and comprehensive health care because they exhibit ‘challenging behaviours’, like Charlotte. In the new NDIS environment, some hospitals have become overly reliant on NDIS-funded services, which can mask entrenched discriminatory beliefs. The belief that people with disability should receive specialist care in separate establishments or services continues to permeate hospital staff, management, and the system as a whole. That the NDIS can support some patients while they are undergoing medical treatment does not absolve health services from their obligation to make reasonable adjustments to provide universally accessible and safe services.

There is a need to shift attitudes and practices of health practitioners to become more inclusive so that all patients with disability are afforded their fundamental human right to health care. Services cannot rely on the NDIS to fill this gap, as the responsibility of hospital services to be able to support patients with cognitive impairment goes beyond the COAG Principles and is clearly covered in the *Australian Charter of Health Care Rights* to provide safe, competent, and high-quality services, regardless of one’s disability status.

OPA welcomes the recent appointment of NDIA Health Liaison Officers (HLOs) whose roles are “to work with hospital and health staff to improve communication between health systems and the NDIS, with the goal of supporting more timely discharge of potential or existing NDIS participants from hospital settings.”[45] HLOs will be focused on building connections across sectors and providing information about the NDIS to hospital staff. OPA’s understanding is that HLOs will not provide direct support to patients with disability outside of linking them to the scheme. OPA hopes that this will solve some issues with accessing NDIS supports, however, it is not intended that HLOs build the capacity of health practitioners to support people with disability.

OPA makes the following recommendation, in line with the recommendations made by the United Nations Committee on the Rights of Persons with Disabilities in its 2019 review of Australia.

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[44] Ibid.

[45] National Disability Insurance Agency, *Health Liaison Officer Factsheet for Government* (December 2019) 1.

Recommendation 9

The Australian Health Practitioner Regulation Agency should ensure that all health practitioners receive training to enhance their capacity to provide accessible and high-quality health care to people with cognitive disability. The training should instruct practitioners how to:

- **actively promote the needs and human rights of people with disability including issues of consent, right to treatment, and capacity**
- **support people with cognitive disability during pre-admission and discharge planning**
- **provide communication advice**
- **liaise with general practitioners, community health and social care teams**
- **identify required supports, including NDIS supports**
- **advise and work with the families and carers of people with disability.**

5. Delays in hospital discharge

The Issues Paper speaks of delays in hospital discharge planning in the context of the NDIS interface. Across its various functions, OPA supports people with disability who are in a hospital setting and observes that discharge planning is often problematic. While several factors contribute to delays in hospital discharge, it should be noted that some predate the NDIS. Notwithstanding this, delays can be lengthened because of a malfunctioning interface between the health and NDIS systems. In this section of the submission, OPA describes the systemic barriers that lead to delays in discharge of people with cognitive disability from hospitals.

5.1. Allocation of a guardian

Guardianship orders received by OPA from VCAT are triaged and prioritised into a waiting list, where they are monitored against fluctuating risk and need. When the guardianship order concerns a represented person who is in hospital, OPA faces somewhat of a dilemma. On the one hand, the person is generally safe from harm and thus would generally be ascribed a lower priority on the waiting list. On the other hand, OPA knows that lengthy hospitalisation tends to lead to poorer outcomes for patients and fewer discharge options for them. It is also costly for hospitals.

In 2016, OPA launched its Guardianship in Hospitals Pilot Project to trial an alternative model of guardianship allocation to expedite the process for hospital patients and increase the support for the healthcare workers involved. The primary aim of the project is to reduce the time between registration of the VCAT order with OPA, allocation of a guardian, first contact by the guardian, and, ultimately, decisions by the guardian. Secondary but equally important aims of the project are to reduce the total length and costs of hospital stays and to diminish the number of inappropriate and/or unsuccessful applications to VCAT for guardianship through education and support for hospital staff.

The latest data from the project shows a decrease by more than half in the average time from the lodgement of the VCAT guardianship order to the allocation of a guardian, that is, from 46.5 days in the control group to 22.9 days in the first full year and a further decline to 16.1 days in the second year of the project. The reduction in waiting time means that patients in the participating networks who have the Public Advocate appointed as their guardian will spend less time exposed to hospital-acquired complications. As a result, these patients have an earlier transition of care to the discharge destination that is best suited to their individual needs.

The project has produced impressive cost-savings for hospitals, estimated at $18,743 per patient and equating to $6 saved per $1 spent by the health network on increased staffing.[46] Across all partner services, the savings to date reach approximately $3,400,000.

Due to its success, the project has received funding to expand its coverage; OPA now employs the equivalent of 2.5 EFT guardians across the Alfred, Eastern, Monash, Northern, and Western Health Networks. As the project progresses, the specialist guardians continue to acquire further experience and skills in supporting patients with increasingly complex medical and guardianship needs, particularly regarding NDIS eligibility and identifying appropriate local supports, which impact on the time it may take for a guardian to be able to make appropriate discharge decisions.

5.2. Access to the NDIS

Notwithstanding the success of the Health Networks Pilot Project, OPA is aware of an increase in the number of applications for guardianship made by hospital staff at the request of the NDIA. Predominantly, these applications are made in respect of patients with cognitive impairment who are seeking to become NDIS participants from within a hospital setting but have no formal decision-making support arrangement in place (e.g. no attorney is appointed).

Individuals who access the NDIS as inpatients in hospital enter the scheme from a unique standpoint. Often, they have been admitted to the service after surviving a catastrophic or traumatic life event (e.g. an unexpected stroke or a vehicle accident) that has resulted in the acquirement of a permanent disability. For the most part, these individuals are new to disability services, but dependent on NDIS funding to be discharged from the hospital and supported in the transition to new and different life circumstances.

In order to become a participant, a person must complete an Access Request Form (ARF). NDIA policy permits a person to make a verbal access request, although OPA is aware that this option is not routinely offered to prospective participants. The NDIA requires an ARF to be completed and signed, ideally by the person who will become a participant, as stated in the legislation. In practice, this requirement can be difficult to comply with, especially for persons with cognitive impairment. In some instance, the ARF can be completed on behalf of a potential participant if the person signing is a parent, legal guardian or representative. These categories of people include both informal and formal (i.e. legal) supports. Therefore, the roles of informal supporters should be recognised in facilitating entry into the scheme. However, hospital services inform OPA that the practices of NDIA frontline staff in this regard are inconsistent.

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[46] Office of the Public Advocate (Vic), *Annual report 2018-19*, 16.

OPA has received recent advice that if a person applies to the scheme on behalf of a potential participant, the NDIA requires evidence of that person's authority to do so and that making an access request is within the boundary of that authority. The NDIA advises that a person with the authority to make an access request may be a person with legal authority or another third party who the prospective participant has consented to act on their behalf.[47]

Based on this advice, it was OPA's understanding that the NDIA was prepared to accept consent for access to the scheme on behalf of a potential participant by either a supporter, an advocate or a service provider in circumstances where there was no conflict of interest.[48] In practice, the NDIA does not always recognise the role of health professionals in supporting potential participants to access the scheme.

If a family member is available to support the potential participant, the NDIA requires the consent from the potential participant for that family member to act on their behalf. In one example, an NDIA staff member refused to accept an ARF signed by a potential participant's parents and, instead, requested a pen be held to her hand to provide a signature while she was minimally conscious.

Most frequently in these circumstances where a person with a cognitive impairment cannot consent to someone singing an ARF on their behalf, NDIA frontline staff have recommended the appointment of a guardian for the sole purpose of signing the ARF (i.e. to consent to the patient accessing the NDIS). The appointment of a guardian for consenting to access to services is in most cases misaligned with the intention of guardianship legislation and indeed the principles of the *National Disability Insurance Scheme Act 2013* (Cth). It also contravenes Article 12 of the CRPD and results in people with cognitive impairment remaining in hospital longer than medically necessary.

OPA understands that the NDIA cannot sign an ARF for a potential participant, but other forms of support can and should be provided to assist with this simple administrative task. Where a potential participant has a significant cognitive disability and is unable to sign the ARF, reasonable adjustments should be undertaken. In a hospital setting, social workers and other staff are well-placed to prepare patients for discharge by supporting them to access the scheme.

OPA previously recommended that the *National Disability Insurance Scheme Act 2013* (Cth) be amended to allow for an access request to be made by a person on behalf of a potential participant. OPA repeats a more recent recommendation made directly in its discussions with the NDIA.

Recommendation 10

The National Disability Insurance Agency's administrative processes, including at the point of access to the scheme, should be sufficiently flexible to enable it to give full effect to its legislative obligation to ensure that participants and potential participants are provided with the support to make and implement their own decisions.

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[47] Advice provided by the NDIA to OPA in written correspondence, dated December 2019.

[48] This is in fact the advice OPA has published in its *Guide to NDIS decision-making*, which is based on the *National Disability Insurance Scheme Act 2013* (Cth) and which was drafted in close consultation with the NDIA. Health services seek to use the guide to inform their work, yet NDIA staff still on occasion reject the advice it contains.

5.3. NDIS and accommodation thin markets

One of the key priorities in discharge planning is for patients to have safe and appropriate accommodation. Some hospital services will not discharge a patient unless a suitable housing option is available for them. In other instances, hospitals face such imminent pressures on beds that they discharge patients to inappropriate and/or short-term settings like motels, which can increase the risk of homelessness or involvement in the criminal justice system. OPA guardians sometimes make the difficult decision to consent to discharge to a less than ideal placement, such as consenting to a young person being discharged from hospital into an aged care facility, for lack of better options.

It is well known that there is an acute housing crisis in Victoria, and this shortage disproportionately affects people with disability. Following deinstitutionalisation in the 1990s and the closure of the remaining standalone institutions, shortfalls in government funding for supported accommodation options have left many people with disability and mental illness without the supports they require.

5.3.1. Long Stay Patient Project

OPA's Long Stay Patient Project sheds light on the impact of accommodation shortages for people with mental illness. 'Long stay patients' are defined as patients spending more than three months in an adult acute unit or more than two years in a Community Care Unit (CCU), Secure Extended Care Unit (SECU) or other secure units such as Thomas Embling Hospital and Mary Guthrie House. Community Visitors collect data for the project on a bi-annual basis and present the results in their annual reports to Parliament.

Since 2008, Community Visitors have identified a remarkable number of patients who appear to be detained under the *Mental Health Act 2014* (Vic) on a long-term basis, despite mental health units not being intended to provide lifelong accommodation and/or support.

Last year, when data was last collected, Community Visitors identified 92 long stay patients across 21 Victorian mental health facilities; this is an increase from 2015-2016 when 65 long stay patients were identified. It is the highest recorded figure since 2010. The duration of stay of the 92 long stay patients ranged from three months to 24 years (in the case of three consumers in a CCU).

In some cases, the person may have been too unwell to move on from the service and in these cases, it can be appropriate for them to continue to receive care. However, many long stay patients spend protracted periods of time in these restricted settings on the sole basis that there is nowhere else for them to go. Indeed, the most consistently cited factor preventing discharge for long stay patients is a shortage of accommodation that could provide the required level of care. In other words, some long stay patients are kept in overly restrictive environments for lack of alternative step-down accommodation options.

The capacity of the mental health system to meet its human rights obligations in line with the Victorian Charter and the CRPD is severely compromised by shortages in community-based accommodation. OPA contends that it is not reasonable to limit a person's rights where their circumstances are dictated by the failure of the service system to provide less restrictive options.

5.3.2. NDIS thin markets

Shortages in supported accommodation for people with disability predate the NDIS reform, as was the case with Oliver who waited more than three months for a DHHS vacancy. However, the transition to the scheme has certainly amplified the issue. In OPA's experience, the retreat of government departments from service delivery has not been executed with the necessary intervention to ensure the NDIS accommodation market supply meets demand. For some participants, this means discharge from hospital is delayed until NDIS services can be put in place to support them in the community.

According to Victoria's health services data, in May 2019, up to 80 patients in public hospital were prevented from being discharged despite being medically ready due to a lack of NDIS supports. The data estimates that patients with disability remain in hospital on average 107 days because of delays with the NDIS.[49] Remaining in the hospital for the sole reason of not having accommodation or supports can result in the prolonged use of restrictive and degrading treatment, as occurred with Oliver.

For participants with cognitive disability and/or complex needs, the implementation of an NDIS plan will often require advocacy as well as the involvement of multiple agencies. One of the greatest losses incurred by the NDIS reform is the fading of a mandated duty of care owed by State governments to provide disability residential services to those in need. Within the consumer-directed model of care of the NDIS, the search for a suitable Specialist Disability Accommodation (SDA) is a more complex and laborious task, in part due to the loss of a central vacancy management function previously administered by the Victorian Department of Health and Human Services (DHHS), resulting from the transfer of DHHS disability accommodation to non-for-profit providers. Delays can be prolonged even once an SDA is sourced, as it is likely that the dwelling will require modifications before it is suitable for a given participant, further delaying move-in date.

Thin markets disproportionately affect participants with complex needs as there is an added complexity whereby providers can refuse to deliver services to any participant they consider 'unsuitable' or, in other words, unattractive due to the complexity of their disability-related needs. These issues could mean that an NDIS participant awaits in hospital for significant periods of time.

OPA's 2018 report, *The Illusion of Choice and Control*, describes the impact of NDIS thin markets on OPA clients and makes recommendations to address them across the NDIS marketplace. The report is provided in appendix to this submission.

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[49] https://www.premier.vic.gov.au/patients-pay-the-price-for-scott-morrisons-botched-ndis/