



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

The Emergency Planning and Response Issues Paper

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Dr Colleen Pearce
Public Advocate
Office of the Public Advocate

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

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

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Abbreviations

DHHS	Victorian Department of Health and Human Services
CHO	Victorian Chief Health Officer
CISO	Correctional Independent Support Officer
ITP	Independent Third Person
IVO	Intervention Order
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDIS Commission	NDIS Quality and Safeguards Commission
NPM	National Preventive Mechanism
OPA	Office of the Public Advocate
OPCAT	Optional Protocol to the Convention Against Torture
Royal Commission	Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability
SDA	Specialist Disability Accommodation
STO	Supervised Treatment Order
VCAT	Victorian Civil and Administrative Tribunal

Recommendations

Recommendation 1

Acknowledging the additional risks and challenges faced by people with cognitive impairment during a public health emergency, the relevant state and territory department should ensure that accessible easy English guidelines to restrictions and explainers (as requested by the sector's peak advocacy bodies) are made available as a priority.

Recommendation 2

Acknowledging the additional risks and challenges faced by people with disability during a public health emergency, Chief Health Officers should seek advice from key disability advocacy groups and the Office of the Public Advocate (or its jurisdictional equivalent) to enable all legally binding directions to be clearly articulated in a way that facilitates compliance by people with disability.

Recommendation 3

During a public health emergency, state and territory governments should convene working groups of relevant industry, consumer and advocacy peak bodies to develop and communicate human rights consistent advice around necessary restrictions and mitigation strategies in group home settings.

Recommendation 4

The NDIA should ensure people with disability (with the help of their supporters) have real choices when making housing decisions about where, how and with whom they live.

Recommendation 5

Easy English and plain English guidance should be developed as a matter of urgency to help allay the fears of people living in congregate care facilities about what will happen to them if an outbreak occurs in their home.

Recommendation 6

The NDIA should fund the development of robustly built disability respite accommodation to ensure the safety and wellbeing of people with disability who need this type of accommodation in a crisis.

Recommendation 7

Government responses to homelessness should be developed that incorporate lessons from the special homelessness measures enacted during the COVID-19 pandemic.

Recommendation 8

State Governments responsible for regulating various disability accommodation settings should actively and pre-emptively consider the kinds of additional supports these services might need during public health emergencies.

Recommendation 9

During a public health emergency, NDIA should consider alternative or interim arrangements for developing and approving plans that would normally require face-to-face allied health or specialist assessments so that people are not trapped without sufficient supports.

Recommendation 10

During a public health emergency, NDIA should consider changes to funding practices that promote flexibility and enable participants to be better supported.

Recommendation 11

During a public health emergency, hospitals and health care providers should ensure that any policies aimed at reducing service demand consider and mitigate their potential impacts on people with disability.

Recommendation 12

DHHS, and other state and territory agencies as required, should revisit the services that are interrupted by the pandemic to see if they can be provided in other ways to promote family and community capacity building and the reunification of families with disability.

Recommendation 13

The Victorian Government should pass emergency provisions to permit the Court to extend reunification timelines legislated by the *Children, Youth and Families Act 2005*. Other jurisdictions should act similarly where relevant.

Recommendation 14

NDIA and government departments with health and disability responsibilities should be preparing for future public health emergencies by enhancing the ability of people with disability to access and use new technologies.

Recommendation 15

During a long-running public emergency, Australian, state and territory health departments should communicate to the public the importance of monitoring and responding to their non-pandemic related health concerns in a timely manner.

Recommendation 16

State and Territory Governments and the NDIS Quality and Safeguards Commission should work collaboratively to explore how safeguards for residents in congregate care can be supplemented during long-running public health emergencies.

Recommendation 17

Corrections Victoria should ensure that the rights protections of the CISO program are embedded in policy and in prison contracts.

Recommendation 18

The Royal Commission should recommend that, wherever possible, safeguarding programs for people with disability be embedded in legislation and government contracts.

Recommendation 19

State and Territory Governments should invest more in public housing and ensure that it meets generally accepted community living standards.

Recommendation 20

State and Territory Governments should invest more in social programs to support and build strong relationships with public housing residents.

Recommendation 21

The Royal Commission should consider recommendations made by the Victorian Ombudsman following her investigation into the tower lockdown, as they come to light.

Recommendation 22

Australian, State and Territory Health Departments should mandate the creation of Scarce Allocation Resource Teams in hospitals across the country in preparation for a health system resources crisis.

1. Introduction

1.1. About the Office of the Public Advocate

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

The Public Advocate has seven functions under the *Guardianship and Administration Act 2019* (Vic),¹ all of which relate to promoting the independence and human rights of people with disability and protecting people with disability from abuse, neglect and exploitation.

To this end, OPA provides a range of critical services for people with cognitive impairment or mental illness, including guardianship, advocacy, and investigation services. In 2018-19, OPA was involved in 1,823 guardianship matters (978 which were new), 404 investigations, and 258 cases requiring advocacy.² Forty-nine per cent of OPA's new guardianship clients were over the age of 65 and more than half (58 per cent) of OPA eligible guardianship clients were National Disability Insurance Scheme (NDIS) participants.³

OPA's two Disability Act officers assist the Office to fulfil its advocacy and safeguarding roles in relation to tenancy rights of people living in disability residential services, including NDIS-funded Specialist Disability Accommodation (SDA). The officers also provide individual advocacy in relation to safeguard protections involving civil detention and compulsory treatment contained within the *Disability Act 2006* (Vic). The officers' interventions remain the largest single contributor to OPA's individual advocacy.⁴

A key function of the Public Advocate is to promote and facilitate public awareness and understanding about the *Guardianship and Administration Act 2019* (Vic) and any other legislation affecting persons with disability or persons who may not have decision-making capacity. To do so, OPA runs a telephone advice service, which answered 13,644 calls in 2018-19. OPA also coordinates a community education program for professional and community audiences across Victoria to engage on a range of topics such as the role of OPA, guardianship and administration, and enduring powers of attorney.

OPA is supported by more than 700 volunteers across four volunteer programs: The Community Visitors Program, the Community Guardian Program, the Independent Third Person Program (ITP Program) and the Corrections Independent Support Officer (CISO) Program. Community Visitors are independent volunteers empowered by law to visit 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 they are not subject to abuse, neglect or exploitation. In their annual report, Community Visitors relate their observations on the quality and safety of the services they visit and make recommendations to the Victorian State Government. More than 400 Community Visitors visit across three streams: disability services, supported residential services (SRS), and mental health services. In 2018-19, Community Visitors made 5527 statutory visits,

¹ *Guardianship and Administration Act 2019* (Vic) s 15.

² Office of the Public Advocate (Vic) *Annual Report 2018-19*, 9.

³ Office of the Public Advocate (Vic) internal program data.

⁴ Office of the Public Advocate (Vic) *Annual Report 2018-19*.

including to sites of criminal and civil detention.⁵ The pandemic has suspended in-person visits and safeguarding services under these programs since the end of February. Some of these programs have been able to continue providing these safeguards in new ways, which will be detailed below.

1.2. OPA's engagement with the Royal Commission

OPA welcomes the continued opportunity to contribute to the Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability (Royal Commission).

The Public Advocate and two Community Visitors appeared as witnesses before the Royal Commission at its December 2019 hearings in Melbourne to speak about violence in group homes. In November 2019, OPA released a report, *I'm too scared to come out of my room*, that was submitted to the Royal Commission in response to the *Group Homes Issues Paper*. In March 2020, OPA contributed a written submission to the Issues Paper on *Health care for people with cognitive disability*. In May 2020, OPA made a written submission in response to the Issues Paper on *The Criminal Justice System*. OPA is also preparing to respond to further requests for information from the Royal Commission, including the Restrictive Practices and Rights and Attitudes papers.

OPA notes that the Royal Commission may also like to review our recent submission to the Aged Care Royal Commission on the impact of COVID-19 on aged care services. The submission is available to download from the OPA website.⁶

Here OPA responds to the Royal Commission's Issues Paper *Emergency Planning and Response* based on research into the particular issues that arise for people with disability in public emergencies and, of course, the experiences from across OPA's frontline program areas during the recent public emergencies: Black Summer and COVID-19.

1.3. About this submission

OPA understands that the Royal Commission is seeking to learn from current and recent public emergencies – the bushfires and the pandemic – to better protect people with disability from suffering abuse, neglect or exploitation during future public emergencies by improving emergency planning and responses.

OPA shares the experiences it has gained during these emergencies with the Royal Commission: stories of individual situations that arose for people with disability, and lessons OPA staff and programs gained from undertaking our various safeguarding roles in this changed world.

This submission defines emergencies as events significant enough to warrant the declaration of a state of emergency which may include natural disasters, civil unrest, pandemics, epidemics or other bio-security risks.

The information included in this submission is drawn largely from the experiences of OPA's front line programs and supplemented on occasion with existing literature on disaster planning and response.

⁵ Office of the Public Advocate (Vic), *Community Visitors Annual Report 2018-19*.

⁶ <https://www.publicadvocate.vic.gov.au/resources/submissions/2020-submission-on-the-impact-of-covid-19-on-the-aged-care-sector>

OPA supports the Commission's published statement of concern about the impact of the COVID-19 pandemic on people with disability. We have seen first-hand a huge range of less than ideal outcomes for people with disability that have arisen from the changes brought about by the pandemic. This is not to say that the changes were not necessarily justified by the emergency, just to highlight the disproportionate impact they have on the lives of people with disability. OPA notes that these poor outcomes often, if not always, stem from a position of systemic disadvantage experienced by the people involved.

It is nonetheless important to note that OPA has also seen the dedication of many people and organisations as they navigate the unprecedented challenges caused by emergencies the nature and size of the bushfires and the pandemic. On the pandemic in particular, time was (and is) of the essence, creating immense challenges for government authorities in the development of a range of measures to combat the spread.

The purpose of this submission is to identify oversights and shortfalls in planning and responding to these emergencies, so that we can learn from these circumstances and improve planning and response in the future.

1.4. Structure of this submission

The submission is organised into six sections (excluding this one). The first section looks at the characteristics of public emergency responses, highlighting the 'mainstream' focus and regular failure to adequately consider at times the implications of these sweeping responses for the lives of people with disability. The second section shares the reality of public emergencies for people with disability, garnered from personal stories shared with front-line staff as well as their perspectives on the changed circumstances of their clients. The third section looks at the specific difficulties people with disability have accessing disability services (both residential and other) and the fourth section looks at their experiences of mainstream services during COVID-19 (with many service systems and offerings much changed by the pandemic). The fifth section examines how OPA's safeguarding roles have adapted to the restrictions imposed by the pandemic. The final section engages in a (currently) theoretical analysis of what should happen during a health system resources crisis and how Australia could plan for one (while doing everything possible to avoid it ever happening).

The content is largely derived from the Victorian context. Where relevant, OPA makes recommendations that could apply to other Australian jurisdictions. The submission includes four case stories drawn from OPA's program areas. All case stories have been de-identified and the names of the individuals have been changed to maintain confidentiality.

2. Characteristics of public emergency responses

Because public emergencies affect everyone, as we saw with COVID-19, the particular needs of people with disability are not front of mind in the crafting of government responses. The needs of the majority are prioritised and government responses centre (sometimes exclusively) on them.

It is possible that, as disaster response research indicates, that there is a moral imperative to prioritise a more utilitarian approach to the use of scarce resources than would normally apply during a state of emergency. This would mirror the utilitarian, 'save the most lives', logic which applies when health care resources are completely overwhelmed by demand

(for example, during a natural disaster or pandemic). If this logic is accepted, and during efforts to control and mitigate the impact of a pandemic it certainly would be hard to argue with, it may help to explain the initial focus on the circumstance of the many in the COVID related government policies Australians have seen during COVID-19.

There are many examples of people with disability being an afterthought. For example, the *Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19)* was published in mid-February while the related *Management and Operational Plan for People with Disability* was published in April. An easy read version of the Management and Operational Plan for People with Disability was also published. Financial aid packages to support the economy and provide an enhanced safety net to people who lost work, like the JobKeeper and JobSeeker initiatives, largely left out people on the Disability Support Pension and Carer payment. And, most confusingly for the disability sector, advice from the newly minted National Cabinet, alongside state and territory Chief Health Officer directions (that have evolved along with the risk levels) failed to clarify what these new laws meant for people with disability who relied on carers for activities of daily living, who lived in congregate care, or who were not able to understand and abide by the directions. While a variety of resources and advice was in time released for providers and people with disability about these changes—by the Australian Department of Health, the Victorian Department of Health and Human Services,⁷ the National Disability Insurance Agency, the NDIS Quality and Safeguards Commission and National Disability Services—this guidance did not adequately address the issues facing disability service providers who offered residential care to people who were unable to comply with social distancing and personal hygiene advice. How should a facilities' duty of care responsibilities interact with the new pandemic related directions when a person could not be depended on to follow the advice around social distancing, for example?

All of these laws and policies have had implications for people with disability, some of them clearly negative and, while often unintended, have resulted in arguably unlawful restrictive interventions and exposure to exploitation and coercion (see sections below).

In the case of COVID-19, of course, OPA congratulates Federal and state governments on the efficacy of their pandemic suppression strategy. Clearly, if this had not been so successful, the health and safety of many people with disability would have been put at much greater risk. Nevertheless, OPA contends that more could have been done to address the significant initial confusion caused by the CHO Directions in a way which would not have reduced the effectiveness of the Australian public health response.

Emergencies in the category of natural disasters hold the same tendencies and tensions: as public announcements about evacuation and preparedness target individuals and households able to make and execute decisions and plans of action for themselves, independently of services. And social and disability services, including residential services, are left to interpret these directions and make decisions to protect both their staff and service users from danger. This tension between business interest and service user wellbeing will be explored in section six below (Accessing disability services in a crisis).

⁷ For example, the *Coronavirus COVID-19 Plan for the Disability Services Sector* published by the Victorian Department of Health and Human Services.

2.1. Confusion and ambiguity

This section explores the impact of system-wide confusions that occur during a public emergency on people with disability. It shows how these various interruptions of 'business as usual' practices are felt disproportionately by people with disability (and other people whose circumstances are outside of mainstream experiences). In part, the greater impact on people with disability is the result of their higher levels of involvement with both criminal and civil justice systems and healthcare systems. In part, it is the result of increased levels of ambiguity that occur during an emergency. This ambiguity can be seen in both legal and practical arenas.

From a practical perspective, the many mainstream services that people with disability engage with day-to-day experienced great upheaval when public health advice caused them to close their doors (wherever possible) or, in the case of hospitals, reframe their goals and practices towards clearing beds and discouraging new admissions. OPA's frontline staff saw multiple negative outcomes for their clients stemming from these changes. These will be detailed in the section on mainstream services. OPA's own staff were faced with confusion over which services they could expect to be offered during the pandemic, with community services in some regions continuing unabated while those in other regions were suspended or went completely online. This is not to say that the changes were not necessarily justified by the emergency, just to highlight the disproportionate impact they have on the lives of people with disability.

Further, OPA is aware that confusion was also apparent among residents of disability services. In some cases, people with significant cognitive impairment may not have been able to understand if someone tried to explain the sudden and restrictive changes to their lives in congregate care. However, anecdotally it has been suggested that some services did not attempt to explain the changes that were being imposed as part of a public health response to the pandemic. Whose job was it to explain that the sudden restrictions being imposed in their homes were not punishments but were happening in homes across Australia? Were accessible easy English resources shared with residents?

Families also expressed fear and concern about the lack of PPE use in congregate care facilities.⁸ Again, a plain English explainer could have been developed and shared across the sector to explain that this was in line with public health advice and was not a failure on the part of the provider to offer a safe service.

Recommendation 1

Acknowledging the additional risks and challenges faced by people with cognitive impairment during a public health emergency, the relevant state and territory department should ensure that accessible easy English guidelines to restrictions and explainers (as requested by the sector's peak advocacy bodies) are made available as a priority.

⁸ The Public Advocate released a *Statement of support for priority access to PPE for disability support workers* on 8 April 2020 <<https://www.publicadvocate.vic.gov.au/about-us/media-centre-2>>.

As an example of good practice, OPA notes here the *COVID-19 Planning Resource for People with Disability Australia*, designed to help people with disability to get the facts about Coronavirus (COVID-19) and make a plan for how they will manage the impact of this situation.⁹

Chief Health Officer directions

From OPA's perspective, one of the initial, yet significant, problems that arose for our frontline staff (and hence for people with disability) stemmed from the ambiguity inherent in the Victorian Chief Health Officer's (CHO) directions. This is notwithstanding resources published and updated regularly by the Victorian DHHS (as one example).¹⁰

The CHO directions, effective from midnight on 21 June 2020, provided much greater clarity around who was considered a 'worker' and who was considered a 'visitor' to a congregate care facility, and eased restrictions around when one can leave their home. The most recent directions, at time of writing, reimposed 'a stage 3 lockdown' arrangement in Greater Melbourne but maintained greater clarity about the conditions that apply in 'care facilities' and in private homes. However, for almost three months there was ambiguity in relation to how these directions should be applied to people with cognitive impairment or who needed assistance with personal care tasks. OPA does note, however, efforts from DHHS and National Disability Services to explain the complexity of the legal directions. It does highlight the challenges bought by the rapid changes experienced and the limited time organisations had to comprehend and implement those changes.

OPA's awareness of this issue came through our engagement with the lives of Represented Persons through our Advocate Guardian Program and through telephone calls to our public advice service. OPA refers to the various problems that arose from these ambiguous directions colloquially as 'front door problems.'

'Front door problems' were the situations that occurred when congregate care facilities, including aged care facilities, disability residential services (including Specialist Disability Accommodation or SDA) and Supported Residential Services (SRS) made changes to their usual practices around access to residents in response to the COVID-19 pandemic.¹¹ There were facilities that went into total lockdown, not allowing residents to leave the premises or people other than facility staff to enter the building. While the Australian Government intervened in the case of aged care facilities, ensuring that relatives and friends could visit residents where they met certain conditions, OPA staff report that some SRS residents

⁹ This planning guide was developed by researchers at The University of Sydney who lead research on disability inclusive disaster risk reduction. It was developed in partnership with the Queenslanders with Disability Network with funding from the Queensland Government Department of Communities, Disability Services and Seniors. For the purposes of COVID-19 planning, and in collaboration with the Australian Government, a nationally relevant guide was published. OPA refers the Commission specifically to the Person-Centred Emergency Preparedness Planning for COVID-19 – For People with Disability: Guide to assist you to develop your own plan for COVID-19 <<https://collaborating4inclusion.org/covid-19-person-centred-emergency-preparedness/>>.

¹⁰ For example, DHHS, Coronavirus (COVID-19) *Fact sheet on Stay at home and isolation directions for Supported Residential Services proprietors and staff* <<https://www.dhhs.vic.gov.au/community-services-all-sector-coronavirus-covid-19>>.

¹¹ Supported residential services (SRS) are privately operated businesses in Victoria that provide accommodation and support for Victorians who need help with everyday activities. Each SRS determines the services it offers and its fee structure: Victoria State Government, *Supported residential services* <<https://www2.health.vic.gov.au/ageing-and-aged-care/supported-residential-services>> accessed 28 July 2020. SRS are referred to as supported residential facilities in some other jurisdictions.

remain in lockdown. In one case, a person who left a disability residential service for a routine overnight family visit was not allowed back in and the family was forced to care for them in an ongoing capacity. OPA notes that the recent July 'lockdown' has resulted in similar responses from care facilities, regardless of the clearer directions.

'Front door problems' also included significant to total limitations on access to residents by service providers who were not employed by the residential facility. For example, residents in aged care, SRSs and some disability residential services have not been able to continue with their usual NDIS funded support workers and activities. Practice has been variable and dependent on decisions made by organisations managing individual facilities and SRS proprietors.

The impact of 'front door problems' has included instances of (arguably) unlawful restrictive practices, coercion in relation to choices about service providers and freedom of movement, and increased opportunities for unreported abuse and neglect due to lack of access by independent informal and formal safeguarding mechanisms.

OPA held concerns very early on, following the release of the first CHO directions, about how they should be interpreted with regard to the lives of people with cognitive impairment. OPA was particularly interested in consent issues around COVID-19 testing and isolation practices people who did not have the capacity to understand what was being asked of them nor to consent.

In our work on these topics OPA developed guidance for our staff, including guardians, the Medical Treatment Decisions team and the advice service, on who has the right to consent for COVID-19 testing. OPA also wrote to the CHO for advice on these matters. For a period, OPA's legal team was unable to provide advice to frontline staff on whether or not the 'front door' practices impacting the people they advocated for were aligned with these directions or were excessive.

The implications of this legal ambiguity for the advocacy efforts of OPA staff were clear, and it is likely that this would have affected other disability advocates and self-advocates in similar ways. OPA guardians reported various attempts to advocate for their clients ('represented persons' under Victoria's Guardianship and Administration Act): to promote access to allied health services or functional assessments to further their NDIS plan reviews and to re-establish long-standing pre-COVID family access arrangements. During this period OPA's Disability Act Officers advocated for people at Supervised Treatment Order (STO) review hearings, and reported concerns with the levels of restrictions that people were being subjected to purportedly due COVID-19 concerns. They also reported that in some matters a lack of progress on issues like a broken pair of glasses from December 2019 were being attributed to COVID-19 community responses. Like other people with disability, people on STOs were reportedly denied access to specialists like behaviour support practitioners and psychiatrists during this time. The Community Visitors program received referrals from the community through OPA advice service, which they investigated (remotely) and escalated through the usual channels.

In all of these matters, the central questions were the same: were the organisational decisions about COVID-19 related changes to business as usual proportionate to the risks involved, could we get better outcomes for clients by challenging these decisions, and, in some cases, did (and do) these new practices entail unlawful restrictive practices?

The question of whether residential services have been overstepping their legal right to limit residents' freedom of movement has not been resolved, although greater clarity on worker access to facilities will no doubt benefit many people. For advocates, a lack of legal clarity can leave them and their clients without a confident way forward when they are not satisfied with the organisational response.

Of course, different legal and regulatory frameworks govern the three main congregate care settings OPA engages with. Of note is the advice provided by the NDIS Quality and Safety Commission (NDIS Commission) in March, stating: 'It is not a regulated [and therefore reportable] restrictive practice if there is a self-isolation order or any other direction to the community as a whole that is issued by the Australian Government Chief Medical Officer or as directed by state and territory Chief Health Officers.' The NDIS Commission also stated that if a provider 'isolates an NDIS participant because you are concerned about their health but there is no directive from a medical practitioner that is in line with the Commonwealth Chief Medical Officer's advice, then this could be a regulated restrictive practice'. This difference, and its implication for emergency planning and responses, will be discussed in more detail in a later section.

OPA observed instances where the CHO's Stay at Home directions resulted in greater restrictions on mobility for people in residential services than they did for people in the broader community. Even people with disability who did not live in residential care were impacted in multiple ways as services they previously relied on were suspended or went online.

Recommendation 2

Acknowledging the additional risks and challenges faced by people with disability during a public health emergency, Chief Health Officers should seek advice from key disability advocacy groups and the Office of the Public Advocate (or its jurisdictional equivalent) to enable all legally binding directions to be clearly articulated in a way that facilitates compliance by people with disability.

2.2. Providers dictate options

The power of organisational policy to dictate the options and lives of people with disability has been apparent during the pandemic. As seen below, some disability residential services providers worked to facilitate access for residents to their usual services within the home while others decided that this was not an option and limited access to the home to their staff only. From OPA's experience engaging with people working across allied health, behavioural specialists and residential services, we believe that in many cases it was organisational policy that drove the types (and mode of delivery) of services offered during COVID-19. While this is nothing new, of course services are responsible for determining what they will offer, consumer choice is greatly constrained during a public health emergency which prevents service users from 'voting with their feet.'

Movement within the residential services sector largely halted, with the exception of aged care (which, anecdotally, forced 14-day isolation periods on new residents). SRS and disability residential services residents were beholden to the decisions of their providers and the vast majority were not taking new residents. For example, OPA staff are aware that, in some of those SRS that had decided on a lockdown approach, residents were free to leave but would not be allowed to return after a day out.

OPA is not unsympathetic to the fraught position residential services providers faced at the onset of the pandemic, understanding that people living in congregate settings were particularly at-risk of contagion and that people with disability were more likely to have underlying health conditions that made them vulnerable to severe forms of the disease and even death. The questions (and regulatory gaps) that we seek to highlight here are those that arise most clearly in an emergency:

- Which organisational priorities are foremost when making decisions that impact the wellbeing of clients? Duty of care? Health and safety of staff? Client wellbeing? Organisational reputational risks?
- Where emergency related orders and directions are in place, what is a reasonable interpretation of those orders where it is unclear how they fit with the lives and service needs of people with disability? What role does perception of risk play in these decisions?
- To whom can SRS residents who have a disability who don't have an NDIS package, advocates and families escalate their concerns to where they feel that resident wellbeing is threatened by organisational restrictions?

Interestingly, the initial response of the aged care sector to COVID-19 was characterised by widespread lockdowns and many facilities banned face-to-face visits with relatives. The aged care sector responded to the concerns raised in the media by families wanting information and access to their loved ones by working together to develop an 'Industry code for visiting residential aged care homes during COVID-19'.¹² This approach was suggested by COTA Australia and provided an opportunity for joint consideration by peak industry bodies of the relevant laws and advice of the Australian Health Protection Principal Committee (AHPPC) as well as the human rights of and risks to residents during the pandemic. The result was a publicly available industry agreed guide for facilities that acknowledged and sought to manage the risks involved while respecting the rights of residents to have some contact with their loved ones as long as risk mitigating conditions were met. The code also specifies options for complaints to the Aged Care Quality and Safeguards Commission.

The NDIS Commission published a variety of online resources including links to updates, training, alerts, and resources for NDIS participants and providers. The guidance published by the NDIS Commission did not provide such specific direction to providers; rather it linked to the Australian Department of Health website and the Victorian DHHS website. The Victorian DHHS published a variety of resources, which are updated regularly, to support the disability and community services sectors.¹³ It is clear that the advice, however, has not resulted in consistent practice across facilities in relation to resident access to external services and freedom of movement.

Where it relates to an NDIS registered (or unregistered provider) and someone thinks that the organisation imposed limitations on resident movement which go beyond the enforceable restrictions imposed on the general community and the specific CHO directions that apply to Victorian care facilities, and they did not follow the necessary processes in

¹² <https://www.cota.org.au/policy/aged-care-reform/agedcarevisitors/> version from 11 May 2020.

¹³ Available at Victoria State Government, Department of Health and Human Services, *Coronavirus (COVID-19)* <<https://www.dhhs.vic.gov.au/coronavirus>>.

relation to regulated restrictive practices, a complaint could be made to the NDIS Commission.

The SRS sector, like aged care and disability residential services, is subject to CHO directions. Their regulatory framework is silent on the issue of restrictive practices. OPA frontline staff report very different responses from different facilities, from complete lockdowns with no community access and threats of eviction for those who do not follow the rules to facilities where residents who may not be capable of following social distancing advice have frequent, unsupervised community access and hygiene and cleaning regimes are poor.

The work of the aged care industry bodies to collaborate and consider together the applicable laws (existing and COVID-19 specific) and the human rights of the residents and develop clear guidelines for the whole sector has been invaluable. In planning and responding to a future pandemic, the disability sector would benefit from public collaboration like that across the aged care sector.

Recommendation 3

During a public health emergency, state and territory governments should convene working groups of relevant industry, consumer and advocacy peak bodies to develop and communicate human rights consistent advice around necessary restrictions and mitigation strategies in group home settings.

OPA notes that the needs of diverse groups could be better met by increased early consultation with key representatives of those groups. The Victorian Government addressed this by establishing the Coronavirus (COVID-19) Disability Taskforce. The purpose of the Taskforce is to contribute expertise to inform effective care and supports for people with disability and reduce risks posed by COVID-19. The Public Advocate sits on this Taskforce, which is chaired by the Minister for Disability, Ageing and Carers, and consists of representatives from across the sector (including DHHS, NDIA and the NDIS Commission). A Taskforce such as this needs to be embedded in emergency planning and responses. Consultations should be ongoing as risk levels change during an emergency.

Such groups are also valuable outside of periods of emergency to help identify and solve emerging and entrenched issues.

2.3. Balancing risks with resident safety

As highlighted in the section above, OPA staff saw some risk averse responses from disability service providers. As discussed above, where the decisions are presented as organisational decisions (and in many cases, relied on questionable interpretations of CHO directions) it can be very difficult to advocate successfully and seek better outcomes for the client. How were advocates or guardians to ensure the services being engaged promote the wellbeing and meet the needs, will and preferences of the person? A sector-wide response, as recommended above, would have helped assuage concerns that responses from some organisations were overly risk averse.

It is clear when it comes to discussions of risk and individual wellbeing (and consideration of a person's will and preference), that congregate care settings create tensions that require consideration. Clearly, community access during a pandemic will always pose some risk of

a resident bringing the disease back to the facility which could potentially infect other residents who have not gone out. Does that mean the people operating the facility have a duty to prevent all community access or limit the number of staff with whom each resident comes into contact with? Some organisations took this view. Others did not. In any such instance it is crucial that residents are consulted on these matters to ascertain their preferences. OPA is not aware of the extent to which this occurred.

Organisations have responsibilities to their staff as well as their residents. This will always be the case. Congregate care settings necessarily result in greater potential for disconnection between the will and preferences of a resident and the organisational policies imposed on them. This is the case even outside a public emergency. This is yet another reason for people with disability to have real choice over where and how they live – it would be easier to accept restrictions imposed to protect your co-residents if you had freely chosen to live with them.

Recommendation 4

The NDIA should ensure people with disability (with the help of their supporters) have real choices when making housing decisions about where, how and with whom they live.

3. The reality of public emergencies for people with disability

Public emergencies bring existing disadvantage into sharp focus. People with disability who require community or disability services to support them to lead full lives are more affected by constrained or confused service delivery and offerings during public emergencies. People who do not require such supports are significantly more likely to be able to successfully navigate a world impacted by a public emergency and get their basic needs met. As discussed above, this is due to their reliance on organisations with a variety of needs to balance (see sections 3.2 and 3.3 and case below). Of course, people who were already struggling with homelessness, health issues, mental illness, social isolation, poverty or personal safety, and who were not sufficiently linked in with services who could help meet their basic needs would likely become even worse off during an emergency.

To have one's opportunities constrained by service provider decisions may well be unavoidable during an emergency, when one is less able to 'vote with their feet', access advocates or have their complaints properly heard due to more pressing matters. This is why a supportive framework, which engages with the relevant laws and human rights, is recommended to assist organisations to make the best decisions possible in difficult circumstances (see, for example, rec 3).

OPA brings to the attention of the Royal Commission a statement by Empowered Lives, 'Supporting Victorians with a disability during COVID-19 restrictions',¹⁴ which was released in the week following Melbourne's second lockdown period and provides further detail on

¹⁴ Empowered Lives, 'Supporting Victorians with a disability during COVID-19 restrictions' (July 2020) Published by the Victorian Council of Social Services, <http://empoweredlives.vcross.org.au/wp-content/uploads/2020/07/Empowered-Lives-Statement-on-COVID-19-Support-for-People-with-Disability-July-2020.pdf>.

many of the impacts on people with disability mentioned above. The statement also includes a call to action, which OPA recommends to the Royal Commission.¹⁵

3.1. No alternative accommodation in a crisis

However, another plank to enable better, less risky outcomes is definitely needed. Many of the problems that occur for people with disability revolve around the lack of availability of an appropriate and accessible backup service or accommodation option. OPA has long advocated for housing and services of last resort options for people with complex needs, particularly those people whose behaviours of concern might threaten existing care arrangements.

During COVID-19 the lack of initial clear fall-back service options and living arrangements have been a source of stress for many people with disability and their families as they worried what might happen if an outbreak occurred in their facility. OPA's legal unit wrestled with the meaning of the CHO directions in relation to the legal grounds for testing and detaining close contacts of a 'known case' who lived or worked in a group home. Community Visitors and Volunteer Programs staff were also very concerned, especially for the wellbeing and safety of people in SRSs. The fact that the State Government has established a specialist team who would be involved in responding to outbreaks, which included trained nurses and infection control specialists, was very assuring. The CHO told OPA that this team would be OPA's go-to in the event of an outbreak that impacted OPA clients, and that they would provide guidance on the complex legal and practical questions that would eventuate. Disability advocates were further informed that the government had also repurposed empty facilities to relocate people with disability to in the event of an outbreak. This helped reassure some groups that people with disability would be taken care of. Others were worried that people with disability who had tested positive to COVID-19 would be potentially sharing this facility with close contacts who were required to undergo isolation, exposing them to more risk of contracting the disease.

Providing clear public guidance on the options available to the specialist team and their key decision-making frameworks could have benefitted people with disability, allaying their fears and ensuring they felt considered and cared for. Indeed, our COVID responses will likely be in place for some time to come. OPA recommends that public guidance and easy English guidance on the framework in place to safely manage outbreaks be developed and released as soon as possible.

OPA notes here a NDIS Commission resource *Coronavirus (COVID-19): Outbreak preparedness, prevention and management*. The resource is intended to support registered providers to understand how to: ensure their workers take reasonable precautions to protect people with disability and themselves, prepare for an outbreak of COVID-19, respond to suspected or confirmed cases in different types of service settings and manage an outbreak of COVID-19. The resource directs providers to review *National guidelines for the prevention, control and public health management of COVID-19 outbreaks in residential settings* (Communicable Diseases Network Australia).

¹⁵ OPA notes here the COVID-19 Planning Resource for People with Disability Australia, designed to help people with disability to get the facts about Coronavirus (COVID-19) and make a plan for how they will manage the impact of this situation.

Recommendation 5

Easy English and plain English guidance should be developed as a matter of urgency to help allay the fears of people living in congregate care facilities about what will happen to them if an outbreak occurs in their home.

Guidance for disability residential service providers, including SDA, on how to make decisions about supporting a resident who needed to self-isolate, was released by DHHS in May 2020.¹⁶ The guide highlights two issues OPA seeks to highlight that have impacted the lives of people living in such settings during a public emergency. The first, the lack of an easy English publication to accompany this document, is highlighted above. The second is that the guidance fails to engage with the reality of the sector when it comes to alternative accommodation options for people living in congregate care, especially those who need to reside in 'robust' accommodation. The reality of the sector is that alternative and crisis accommodation options are scarce, and that individual disability accommodation providers are not resourced to bear the burden of emergency (or any) relocations. The flowchart in this publication, which discusses what should happen to the various groups of people with disability who will need to self-isolate and the services and asset issues that would make this difficult in their usual residence, ends with the following statement:

'New external accommodation options sourced by provider suitable for effective isolation, supported by some existing staff. May include repurposing of existing provider managed facilities (e.g. empty STAA facilities)¹⁷

This statement ignores the reality of the independent and private providers of disability residential services who make up the bulk of providers in this cohort. Very few of these providers would have the resources to offer their residents alternative accommodation. Without the State Government stepping in to offer access to alternative accommodation to those who had nowhere else to live (as they did prior to the NDIS) or state or federal funding of motel or other alternative accommodation (if this would work for the particular client facing isolation) this guidance would not be feasible advice to most providers.

The lack of engagement with this issue in the document highlights what has been seen much more clearly under the pressures of COVID-19: who is ultimately responsible for ensuring vulnerable people are housed and cared for? This question remains even where public emergencies end. A public emergency, however, clearly demonstrates the need for disability services to have provider of last resort capacity.

The following story exemplifies the additional risks that accrue to people with disability who live in a residential service without a plan for relocation in a crisis. It also highlights the balancing of risks that can occur in a crisis, that could be allayed by earlier planning.

During the 2019-2020 bushfires, one community found itself under threat from fires burning in nearby bushland. While the general community was instructed to evacuate from their homes and seek shelter elsewhere, people with disability living in disability residential care boarded a bus and drove to the nearby shopping district where they sat in the bus, waiting for hours for the threat to pass. Another person

¹⁶ Department of Health and Human Services (Vic), 'Coronavirus (COVID-19) isolation management in disability accommodation services', May 2020, <https://www.dhhs.vic.gov.au/information-community-services-coronavirus-covid-19#centre-based-disability-services>

¹⁷ Ibid, 4.

with disability, who lived alone with 24/7 staffing and who was known to have significant behaviours of concern, was not evacuated. The plan was for that person to remain in their home until evacuation was necessary. Emergency management personnel onsite chose to leave their evacuation to the last possible moment rather than evacuate them to a local hospital as a precautionary measure, which was the alternate accommodation option available to them at the time.¹⁸

This story highlights the additional and disproportionate risks borne by people living in disability residential services, who have no clear alternative accommodation options available to them. These potentially include delayed evacuations contributing to an increased risk to their personal safety, as well as abuse and neglect during the restrictive intervention of detaining them on a bus (instead of taking them to a safe community setting or other respite service).

OPA recognises that the decision to delay the evacuation of the individual with behaviours of concern may well have been the best one at the time given the alternative accommodation options available to them, given also the unclear and inconsistent way the person may have responded to this particular situation. However, OPA points out that if robust build respite accommodation had been available (as we have previously recommended) then the risks and benefits of moving the individual may have shifted.

Recommendation 6

The NDIA should fund the development of robustly built disability respite accommodation to ensure the safety and wellbeing of people with disability who need this type of accommodation in a crisis.

3.2. Homelessness and the pandemic

The Victorian State Government's response to addressing homelessness during the pandemic has been very effective, perhaps crossing into territory that would previously have been considered too difficult. This is understandable as part of the nationwide public health response, as people who are homeless are clearly unable to obey 'stay at home' orders and would therefore have increased the number of people in the community who were mobile and potentially able to transmit the virus to others.

OPA notes that many homeless Victorians living on the streets were moved by the government into hotels to help mitigate the spread of the virus. Like advocacy and support agencies working in the homelessness sector, OPA was concerned that no plan had been shared about how the government plans to transition these people out of hotels when the threat has passed. OPA notes the government has recently extended current hotel accommodation until at least April 2021, which OPA, and the key peak body Council to Homeless Persons, welcomes.¹⁹

We know that homelessness disproportionately affects people with psychosocial disability, and that homelessness negatively impacts people's health and safety outcomes. It is

¹⁸ This example comes from personal communication with an OPA Disability Act Officer.

¹⁹ OPA notes the further response from the Council on Homeless Persons, in welcoming the continued hotel scheme and move towards rentals, reinforcing that investment in social housing needs to continue to help people once their private lease expires: "Victoria's homeless hotel program extended" *The Times*, 28 July 2020 <<https://www.victorharbortimes.com.au/story/6852452/victorias-homeless-hotel-program-extended/>>.

difficult to hear that housing people is a priority (and doable) in a time of public health crisis but not at other times.

The Commission's brief is to enhance social protections to prevent abuse, violence, neglect and exploitation of people with disability. While neglect is usually narrowly interpreted as occurring in a relationship between individuals, OPA suggests that homelessness among people with disability is an instance of systemic neglect that bears investigation.

Recommendation 7

Government responses to homelessness should be developed that incorporate lessons from the special homelessness measures enacted during the COVID-19 pandemic.

3.3. People with disability living in poverty

The cost of living for people with disability is significantly higher than for those without. Nevertheless, when, during COVID-19, the Australian Government decided to double JobSeeker payments (and bring in JobKeeper) to help many Australians (individuals and businesses) to financially survive the economic downturn, they did not increase the Disability Support Pension nor the Carer Allowance or Payment. Centrelink did pay first and second Economic Support Payments (COVID-19 economic response) to people on these allowances, but note they also went to people on JobSeeker.

Poverty is a known risk factor for a range of negative health, justice and education outcomes, including for children living in those households. Poverty also can contribute to experiences of social isolation and financial stressors can have serious mental health implications.

Addressing these systemic issues is central to providing people with disability the protection from neglect and abuse that they deserve. These systemic gaps need to be filled by better access to temporary crisis accommodation, enhanced access to social and public housing (including by building more stock), and income subsidies that raise people with disability out of poverty. The onus is on government to plan ahead and prevent, as far as possible, the disproportionate impacts we see accruing to people with disability during public emergencies.

4. Accessing disability services during a public emergency

Disability services in Australia have become increasingly diversified in offerings and ownership since the introduction of the NDIS. This has been a good thing for many Australians with disability, particularly for those people who do not have a cognitive impairment or who have strong independent advocates to help them navigate the new system. OPA has stated many times that 'thin markets' for people with complex needs and behaviours of concern and a lack of independent advocacy and supported decision-making services make outcomes under the NDIS uneven at best. The current public emergency has only multiplied these poor outcomes (or systemic neglect), along with increased risks to individuals of exploitation and abuse.

OPA has seen high levels of confusion among people with disability in relation to variations and cancellations of regular services: from day programs to allied health. OPA staff have

experienced confusion as different organisations and services appeared to interpret the laws and public health advice very differently from those with similar offerings. In part this has stemmed from the unclear CHO directions which were in operation from the end of March into June 2020 (discussed above). In part, this confusion was amplified by a lack of sufficient support from the sector's various funders and regulators for providers to understand and respond to the specific characteristics of COVID-19 and related new laws.

It is true that the funders, regulators and oversight bodies, including the NDIA, NDIS Commission, Victorian DHHS, DOH and the Aged Care Quality and Safety Commission, have made multiple resources publicly available to providers responding to this emergency. It is also true that the contractual scope and legal remit of these bodies may not require them to provide more assistance than they already have. OPA notes of course, that collectively the intention would be to cover the relevant matters. Nevertheless, OPA and other advocacy bodies have numerous examples that demonstrate the risks to the safety and human rights of people with disability where individual providers are left to interpret unclear new laws (even with guidance) and balance their duty of care responsibilities with the human rights of service users during an unprecedented public emergency.

With everyone scrambling to adapt to operating their businesses during a public health emergency it is unsurprising that many have struggled to meet their responsibilities under these conditions.

4.1. Congregate care settings

With some notable exceptions, OPA has seen congregate care facilities in aged care, disability group home and SRS sectors doing the best they know how within the framework of existing laws, regulations and new public health restrictions, with a particular focus on their duty of care responsibilities to clients and staff. As discussed above, during a public health emergency there are inherent conflicts between an organisation's responsibilities to their staff and their residents (especially where residents require care that involves close contact) and between protecting and promoting the human rights of one resident as opposed to the rights and safety of all the co-residents in a single home/facility.

One of the ways this conflict has played out, and continues to play out, is in organisational 'front door' policies. The following example is used to explore some of the questions about whether certain decisions made at an organisational level might have constituted unlawful restrictive practices during this emergency.

Joseph is middle-aged, has autism and is largely non-verbal and lives in a group home. He spent most of his life in an institution where day program was an integral part of his life. Those who know him best say that his day program provides him with a sense of purpose and belonging, and he looks forward to the opportunities that day program provides for him to contribute to the wellbeing of the group.

Joseph's day program provider shut down temporarily in the early days of the Australian outbreak. Joseph's care team anticipated that this break in his routine would cause an escalation in his behaviours of concern and soon began work on finding a stable program option to replace day program. During these discussions it was clear that Joseph's residential service provider was very concerned by the idea of Joseph contracting COVID-19 while he was out and bringing it home.

When the day program decided to reopen with much reduced operating capacity, they offered Joseph one of the first places, recognising how important the program was to him. Despite the agreement of the OPA guardian and the support of the care team, and all the public health risk mitigation procedures documented by the day program, the residential service vacillated and prevented Joseph from accepting the place. The day program offered the place to another participant before the group home provider assented. At the time of writing, Joseph has been at home for more than three months.

Joseph's OPA guardian has another client with similar needs, who also lives in a group home. Karl's group home is run by a different organisation. This organisation approached Karl's regular day program provider (which had also ceased its program) and organised for them to provide Karl with an in-house service. The facility manages COVID-19 risks with protocols around the number of people who can be in the house at one time and around cleaning. Karl has access to their day program, and a continuance of their routine as far as possible under COVID restrictions.

The guardian asks: Why can't Joseph have what Karl has?

The story above demonstrates that organisation level differences in risk aversity, interpretation of the CHO directions, and beliefs about their organisation's duty of care result in starkly different practices and outcomes for clients in congregate care settings.

Joseph's provider organisation adopted a high-level risk averse approach to keeping COVID-19 out of its residential services. The policy was adopted across all its residences irrespective of the needs of particular residents.

It was OPA's view that Joseph's residential service provider was imposing more restrictive conditions than were specified under the CHO directions, although there was ambiguity in the interpretation of the directions. OPA sought to clarify the interpretation with the CHO but this was not resolved at the time the first lockdown concluded. If the restrictions were additional to those set out in the CHO directions, it is OPA's view that this would constitute an unlawful restrictive practice.

There were other residential service organisations that, like Karl's, maintained a 'front door' policy that was less restrictive than Joseph's.

As stated above, OPA sought clarification from the CHO on the meaning of the directions that have been interpreted in widely divergent ways by congregate care providers. OPA did not take this, or the many other, potentially unlawful restrictive practices caused by extremely risk averse organisations to the NDIS Commission. Going forward, with clearer directions and lifting of more restrictions, OPA would consider bringing these types of complaints to the NDIS Commission. (See Recommendation 2.)

The human rights issue of restrictive practices also haunts sectors which have no regulatory framework. During a pandemic health and safety risks (or rights) can be added to a person's right to freedom of movement.

The Supported Residential Services (SRS) sector is one such sector (lacking a regulatory framework for restrictive practices). OPA and Community Visitors have long-held and well-

documented concerns for the safety and wellbeing of people living in SRSs, especially pension-level settings which accommodate people with disability, ABI and mental health issues, have high resident to staff ratios, poorly trained staff and few resources. OPA's Volunteer Programs have also raised concerns about potentially exploitative situations arising where SRS proprietors begin providing NDIS services to their residents: effectively a captive market. Prior to COVID-19, OPA staff were aware of multiple situations where SRS proprietors hold the power to evict residents who do not agree to using NDIS funded services or support coordination being offered by the proprietor.

These exploitation, safety, neglect and abuse issues that were present pre-COVID remain, and in many cases have likely been heightened by COVID-19 related restrictions on face-to-face contact and freedom of movement during lockdown periods. OPA's Volunteer Programs report some SRS facilities have effectively locked the front door, saying that if residents go out for the day that they will not be let back in. This meant at least one resident was not able to attend paid employment. Some other SRSs with residents with more behavioural issues chose not to lock the front door, and Community Visitors' reported that residents unable to understand or comply with lockdown and social distancing requirements continued to access the community as usual. Community Visitors also shared concerns about the level of support provided to residents to maintain COVID-19 recommended standards of personal hygiene, as well as some facilities which did not report undertaking more cleaning of shared facilities and often used surfaces than usual.

COVID-19 restrictions also reduced access to services including mental health, community access, and allied health service delivery. Pension-level SRS residents would also be less likely than most to own their own technology that might enable them to access online services.

OPA's Community Visitors program has undertaken phone 'visits' to SRS, checking in with proprietors about how things are going in their facilities. Logistically, these phone visits are limited to seeking the perspective of the SRS manager or proprietor and are dependent on how much that person is willing to share about the current goings on. OPA staff supporting this program shared the real risks to the tenancies of SRS residents who might be observed by the proprietor to complain about their circumstances. This is one reason that OPA does not seek the views of residents during these phone visits. Obviously, when Community Visitors were able to conduct 'in person' visits private conversations could be held with residents out of earshot of SRS staff. OPA does encourage SRS residents to call them directly with their concerns. While OPA has made efforts to maintain contact, and SRS providers and staff have participated telephone visits, it remains that SRS residents benefit more from face-to-face visits.

The Community Visitor program knows of multiple people who have been evicted from SRSs since March but have no capacity to find out what happened to them.

Some SRSs were initially unable to make bulk food purchases during the periods where supermarkets placed limits on purchases of some items. DHHS had given proprietors a letter to help them communicate their right and need to make bulk purchases.

Some pension-level SRSs are supported by the SAVVI program, for which government funds community service organisations to undertake outreach support to SRS in the region. OPA is aware that while some organisations have done great work under this program,

including during COVID-19, some services in other regions have not been well managed and call on DHHS to more rigorously oversee these contracts.

In both these examples, stronger regulation of SAVVI funds and greater support from DHHS in managing the new challenges facing SRSs under COVID-19 (for example, by reaching out to major supermarket chains to explain the needs of SRSs) could have made people's lives better. The skills and capacities required to successfully manage disability congregate care settings under a 'business as usual' period are clearly fewer than needed during a public health crisis. Regulators should recognise and prepare for these eventualities, and they must be prepared to take a more active role than is needed when things are 'business as usual'.

Recommendation 8

State Governments responsible for regulating various disability accommodation settings should actively and pre-emptively consider the kinds of additional supports these services might need during public health emergencies.

Aged care settings have been heavily impacted by the second wave of COVID-19. At the time of writing, COVID-19 cases have been identified in more than 60 aged care facilities across Victoria. As with other service arenas, many of the usual pathways into and out of aged care and respite beds have been made more difficult or cut off by COVID-19 restrictions. For example, earlier in the pandemic, one of OPA's clients was placed into aged care respite by their support coordinator, who was worried that services to the home may be suspended during the pandemic. In this case, and others, less restrictive options may have been curtailed by service reactions to COVID-19 restrictions.

To manage these difficulties, OPA staff report that in many cases the Aged Care Assessment Service (ACAS) has given multiple extensions to respite placements – likely knowing that functional assessments and exploration of other housing options is very difficult at this time. This has unfortunately resulted in some people remaining 'in limbo' for many months. Or, as demonstrated by the story below, COVID-19 related hurdles to exploring less restrictive options may have resulted in poorer outcomes for clients:

Toni, who has advanced dementia, was placed in respite at an aged care facility when her carer decided they could no longer provide care. A guardian was appointed to decide where she should live. While another family member wanted to look after Toni at home, COVID-related restrictions at the aged care facility prevented the family member from doing carer training at the facility with Toni. Neither could Toni be assessed by the OT at her family member's home, as the facility would have insisted on a 14-day quarantine period when she returned and the guardian felt that would be too onerous for Toni. Without the ability to assess the likely success of this living option, the guardian has since successfully sought three extensions from ACAS of Toni's respite placement. Toni is now receiving palliative care at the aged care facility.

Aged care facilities have also wrestled with the same difficult questions as other congregate care settings. OPA's advice service has received calls from some aged care facilities who were struggling with how to manage residents who were mobile and going out into the community. These were residents who didn't understand the risks of COVID-19 transmission, nor how to mitigate the risks, and they were coming home to the facility

potentially carrying the virus. Some facilities reported to OPA that they were giving those residents different areas to eat in to try and separate them from other residents without using restrictive interventions to keep them locked up.

4.2. Non-residential services

OPA guardians, who may hold 'access to services' powers in relation to their clients, have experienced a great deal of confusion due to regional and provider inconsistencies in relation to how and if they decide to continue to offer their regular services during the COVID-19 pandemic. As discussed above, in relation to residential disability services, organisational decision-making with a focus on staff safety and, also likely, a 'do no harm' to clients approach meant many disability services ceased face-to-face service delivery. OPA staff report this has been the case for Occupational Therapists, neuropsychologists and also some behaviour support specialists. Some support workers who previously provided community access supports now provide social contact using technology – for example, reading the newspaper or other materials to clients or just having a chat.

Again, because service providers are having to balance their duty of care for their staff with the risks and benefits of face-to-face service delivery to clients, decisions are patchwork and organisation specific.

Here there are two key cohorts who are seriously disadvantaged and perhaps systematically neglected by the public health advice to shift to online service delivery like telehealth. The first group include all those people for whom online engagement is not appropriate or effective. This may be because of their disability, poverty, or because of the lack of support they have to utilise available technological solutions. The second group include all the people waiting on functional assessments or behaviour support specialists which are necessary to move forward on NDIS plan development or plan reviews. This limited access to face-to-face assessments means that the detail required by NDIA planners is not able to be gathered and so participants (or future participants) are stuck without appropriate supports, or without the approvals needed to seek more appropriate living arrangements. As COVID-19 related lockdowns are re-established here in Melbourne, some people will have been without appropriate supports for four months or more, with no certainty about when face-to-face assessments will be possible.

OPA notes the changes announced by the NDIA early in the pandemic, and at various stages throughout.²⁰ OPA also notes that the NDIA also published an Easy Read version of the changes to the way the NDIS works for participants. OPA also makes the following recommendations.

Recommendation 9

During a public health emergency, NDIA should consider alternative or interim arrangements for developing and approving plans that would normally require face-to-face allied health or specialist assessments so that people are not trapped without sufficient supports.

²⁰ NDIS, *For participants – coronavirus (COVID-19)* "What is the NDIS doing to help participants?" <<https://www.ndis.gov.au/coronavirus/participants-coronavirus-covid-19>> accessed 28 June 2020.

Recommendation 10

During a public health emergency, NDIA should consider changes to funding practices that promote flexibility and enable participants to be better supported.

5. Mainstream services and the pandemic

Along with everything else in our society, mainstream service delivery has been strongly impacted by the pandemic. In preparation for anticipated pressures on the health system, elective surgery offerings were paused and significant efforts were made to clear hospital beds. General Practitioners, outpatient clinics and community mental health services rapidly embraced telehealth services to slow transmission of the virus. As mentioned above, some people with disability, and particularly people with significant cognitive impairment, would not be well served by moves to telehealth or online service delivery. In Australia and overseas, people have avoided attending health settings (most likely) due to fears of virus transmission in those settings. This may have long-term health impacts if people do not obtain early diagnoses of new health conditions. People with underlying health conditions, including people with disability, may have been even more reticent to attend health care settings due to the larger risk COVID-19 poses to their health.

Overall, OPA staff have noted significant practice changes and impacts on 'business as usual'. This has resulted in unforeseen and sometimes unmitigated negative impacts on OPA clients in mainstream health settings, including hospital and ambulance settings, and in criminal and civil justice systems. Along with our anecdotal experiences we are aware that limitations on these services will impact disproportionately on people with disability, including Aboriginal and Torres Strait Islanders, because they are more frequently engaged in those systems and services.

5.1. Health care settings

The shift to telehealth worked well for some people by providing an additional and safe option to access healthcare. One guardian shared that a telehealth appointment with a hospital clinic had worked really well for one of their clients, as they did not have to sit for hours in the hospital waiting room feeling anxious about the different space. Apart from the time savings offered by telehealth, people who like routines and familiar environments can also benefit.

Decisions made by hospitals to prepare for a COVID-19 related surge involved clearing beds wherever possible, postponing elective surgeries, and generally trying to discourage new admissions. OPA's Hospitals Team works with hospitals to expedite discharge decisions where possible, as such they have been well aligned with COVID-19 related hospital mandates. While discharge of patients to aged care facilities has continued, with many new residents required to quarantine in their rooms for 14 days on arrival, discharges where the person requires new supports to their homes or are trialling living with family members are made more complicated by the pandemic. This is because of the lack of access to functional assessments and constraints on movements of people (for example, to go and visit potential homes). From OPA's perspective, both bed-based and home-based Transition Care Programs appear to be operating as usual.

Encouragingly, OPA staff report that NDIS hospital liaison officers expedited access requests for potential NDIS participants stuck in hospital.

OPA is aware of at least two clients who were negatively impacted by pandemic-related hospital policy of relocating clients away from the two designated 'COVID hospitals' in Melbourne. For one person this meant being transferred to the other side of the city from their family and remaining there for months. For another client, the move from a Transition Care Program in a well-resourced major hospital to another centre was perceived as providing a poorer quality service and impacting on their recovery.

Ambulance services have also been impacted by pandemic responses, as calls are more stringently triaged in an attempt to reduce unnecessary hospital use and admissions. At least two people known to OPA who are repeat users of ambulance services have not been able to access appropriate care during the pandemic. Guardians report that people with mental illness who frequently use emergency departments and ambulance services are being pushed through the system more rapidly than usual. This practice has had negative mental (and even physical) health outcomes for some of these individuals. One person with well-known self-harming behaviours called 000 and was assessed by 'Nurse on call' and told that their injuries were not serious enough to warrant an ambulance; they then inflicted further harm on themselves.

OPA guardians highlighted their concerns for their clients, noting the impact of changes to routine and withdrawal of regular face-to-face contacts as particularly stressful and isolating for many people with disability. Like everyone else, people with disability are experiencing the emotional toll of loneliness, however some have less capacity to regulate their moods and responses. This could well increase their need for mental health or emergency services.

While on the face of it these policies may make sense during a pandemic, a similar point can be made in this realm as we made above about the CHO directions. Application of these health sector policies to people with disability who have pre-existing health issues, insufficient community supports or extreme social isolation will have a disproportionate impact and potentially lifelong consequences. OPA suggests that there may be value in reconsidering these policies, particularly when the health system is not experiencing unmanageable levels of demand for services. The ethics and decision framework that should apply in such situations are discussed in section 7 below.

Recommendation 11

During a public health emergency, hospitals and health care providers should ensure that any policies aimed at reducing service demand consider and mitigate their potential impacts on people with disability.

In line with the 'front door' problems discussed above, OPA understands that hospitals and mental health units have also grappled with the question of how to manage patients who are unable to comply with recommended social distancing practices or limit their exposure to the virus in the community. In one case the provider sought to discharge the person, although the guardian refused to consent on the grounds that it would be discharge to homelessness. In another case, a hospital considered isolating and effectively detaining a mobile patient in a private room to try and prevent her becoming infected in the community. Would a person without a guardian or skilled advocate be more likely to be subject to such

unlawful restrictive interventions? A similar situation played out with a residential service seeking the approval of the guardian to seek a detention order from the chief practitioner as a preventative measure, again for a mobile person who was unable to comply with the distancing and hygiene advice.

5.2. Justice settings

The pandemic has and continues to have a substantial impact on courts and tribunals all around Australia.

Given the legislative role of the Public Advocate, OPA staff have a lot of contact with the Victorian Civil and Administrative Tribunal's (VCAT) Human Rights List in relation to guardianship, tenancy rights and civil detention matters. Like many other settings, including hospital and disability sector care team meetings, VCAT has grappled with how to successfully conduct phone and, more recently, some Zoom hearings. Expected communication difficulties arise in some contested hearings with people speaking over each other and the member not knowing who is saying what. This has made it harder in some instances to get the necessary information during hearings. OPA considers that this has had flow on effects on the volume of investigation matters being referred to OPA, which will be discussed below.

Like other sectors, a rapid upskilling has occurred in relation to the use of technology and this has made hearings using Zoom possible where participants require it.

The impact of courts moving online has contributed to longer waits for the resolution of some justice issues during this time.

One guardian awaiting a hearing regarding an interim intervention order at the Magistrate's Court reported difficulties making contact with the court, due to an incorrect phone number and changes to normal communication channels. The guardian was told that the scheduled hearing had been adjourned, then on the day of the adjourned hearing was told it was going ahead. The client was unprepared for the hearing and did not have supports in place so that hearing had to be adjourned for a second time. Altogether, court delays and the client's distress about not being able to see their family member during this time saw the client's mental health and behaviours worsen.

OPA is aware that, in another of the positive homelessness responses provoked by the pandemic, Corrections have refitted the Maribyrnong Detention Centre to provide short-term post-release accommodation for people coming out of jail who would otherwise be at risk of homelessness. In the past, they would have simply been released to the street. Again, providing appropriate accommodation to our most vulnerable people should be a priority at all times, and not limited to a pandemic. With better general infrastructure in place the arrival of a pandemic would result in less disruption to people's lives.

5.3. Child protection

OPA has maintained a special interest in the circumstances of parents with disability who are separated from their children under Child Protection. During the first lockdown period, under COVID-19 restrictions, court-ordered contact between children and their families was

suspended. It is likely that this has also occurred during the second lockdown. OPA is very concerned by anecdotal evidence that suggests even where lockdown conditions are eased that contact between parents and children has been extremely limited or even completely prevented.

OPA notes that COVID-19 will also have substantially impacted on parents' abilities to address the issues of concern (due to decreased access to support services) and safely resume their parental role within the legislated time limits. OPA calls on DHHS to work co-operatively with the Court, families and professional agencies to find ways of building family and community capacity so that this pandemic does not cause a surge of families permanently torn apart.

Further, OPA proposes that all timelines for the reunification of children with their families be suspended for as long as it takes to give families a genuine chance to be reunited.

Recommendation 12

DHHS, and other state and territory agencies as required, should revisit the services that are interrupted by the pandemic to see if they can be provided in other ways to promote family and community capacity building and the reunification of families with disability.

Recommendation 13

The Victorian Government should pass emergency provisions to permit the Court to extend reunification timelines legislated by the *Children, Youth and Families Act 2005*. Other jurisdictions should act similarly where relevant.

6. Safeguarding in a crisis

During the pandemic many organisations who have safeguarding responsibilities have struggled to maintain the protections their work previously offered. For example, the United Nations Subcommittee on Prevention of Torture suspended their own visits in mid-March 2020 due to the pandemic, citing the 'do no harm' principle. However, the Committee stresses the increased importance of oversight and monitoring by in-country National Preventative Mechanisms (NPMs) during this worldwide pandemic, citing the 'very real pressures that detention systems and those responsible for them now face'²¹. They summarise their position here:

The Subcommittee and national preventive mechanisms must be conscious of the "do no harm" principle as they undertake their work. This may mean that national preventive mechanisms should adapt their working methods to meet the situation caused by the pandemic in order to safeguard the public; staff and personnel working in detention facilities, including healthcare staff; detainees; and themselves. The overriding criterion must be that of effectiveness in securing the prevention of ill-treatment of those subject to detaining measures.²² OPA, and other safeguarding organisations, have been forced to

²¹ United Nations Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, 'Advice of the Subcommittee to States parties and national preventive mechanisms relating to the coronavirus disease (COVID-19) pandemic', CAT/OP/10, 2.

²² Ibid, 5.

think creatively about how to undertake safeguarding work in the context of the limiting circumstances of the pandemic, and, similarly, believe the pandemic brings additional safety and human rights risks to people with disability. In our context, 'stay at home' orders reduce informal monitoring of vulnerable Victorians in private homes, as do strict 'front door' policies in aged care or other residential services. OPA's Advice Service note a three-fold increase in notifications made via this service to OPA's Community Visitors Program during the pandemic. These notifications demonstrate the number of people concerned about the circumstances of family and friends they can no longer visit.

The very real risk of widespread transmission of COVID-19 to vulnerable people living in congregate care settings has now eventuated in the aged care sector in Victoria. OPA notes here the devastation and distress being experienced by those people living in aged care facilities, their families and loved ones, and nursing and care staff.

Below we document the challenges and responses of OPA's various safeguarding arms: guardianship, investigations and medical treatment decisions, OPA's Volunteer Programs and Disability Act Officers. And while the Advice Service is not technically a safeguarding program, we discuss their role during the pandemic.

6.1. Guardianship

Guided by a 'do no harm' principle, OPA decided to cease face-to-face visits and meetings between its staff and clients unless it was impossible, without undertaking a visit, to know if the person was safe or to have enough information to make a guardianship decision. This decision was made after careful deliberation and balancing of risks. Also, some OPA staff visits have been denied by facility staff due to perceived risk of virus transmission. Hence, in most situations staff are reliant on technological solutions to communicate with clients, or, alternatively, on the people around them to describe the person's situation and preferences.

Technology has enabled effective communication with many clients, particularly with verbal and younger clients. Noting that access to video call technology should be considered a human right in this time and place, staff also say that elderly and non-verbal people have often been difficult to engage online. The Commission will not be surprised that the ability of substitute decision-makers to ascertain the will and preferences of clients who cannot engage with them effectively online has been a real challenge during the pandemic. Decision-makers find themselves reliant on the accounts of those around the person, which may occasionally be misleading. Multiple OPA staff noted that being in the room with someone, and seeing their home circumstances and relationships with their carers first-hand, provided multiple clues that just were not available from a phone call or a video chat. This meant that OPA staff were uncomfortable about relying on these forms of contact for new clients.

OPA staff also had more difficulty being confident of a person's needs, will and preferences in circumstances where their clients resided outside well-regulated settings like nursing homes, health care settings and disability residential services. This is because, in the absence of face-to-face visiting, guardians were less likely to have reliable independent informants around the person.

Guardians and other OPA staff see video technology as helping them to connect with clients and build a fuller picture of their lives (and indeed, OPA is likely to utilise technology more into the future), however, this option is not always available and will never provide as

much information as a face-to-face visit. OPA nevertheless supports efforts to increase access and build skills of people with disability (and their supporters) in technology use to help them stay connected with friends and services during the pandemic.

Recommendation 14

NDIA and government departments with health and disability responsibilities should be preparing for future public health emergencies by enhancing the ability of people with disability to access and use new technologies.

Guardians are often reliant on the engagement of other services with the client to help them understand what is going on, during public emergencies some of these services are justifiably suspended.

Importantly, overall, guardians report being able to gather enough information and ascertain clients' will and preferences sufficiently (without face-to-face visits) to make the decisions they have to make. In some cases, these decisions are interim decisions where, for example, pandemic related constraints prevent the necessary assessments or trials of new care arrangements. While being able to make do with what resources they have, all Guardians look forward to a time when face-to-face visits are less constrained. Where assessed as justified and necessary, face-to-face visits are still undertaken with health precautions.

The new *Guardianship and Administration Act 2019* (Vic) requires guardians (and administrators), when making decisions, to give all practicable and appropriate effect to the represented persons will and preference if these are known, and, if not, to what they believe these are likely to be. The current public health emergency has made this more difficult.

The significant impact of the pandemic on VCAT capacity to hold in-person hearings has resulted in instances where hearing the voices of people with disability has been difficult. The telephone and video call VCAT hearings are more difficult for some people with disability to engage with, and there are more hurdles for OPA staff seeking the views of the represented person (under guardianship).

In relation to Victoria's regular fire season, OPA has sought to ensure that all of their clients are on the State's vulnerable persons register ahead of the fire season. Guardians have been asked for the past two years to identify clients in risk areas ahead of the fire season. The register records what assistance people would need to leave if they had to so if a person needs to be evacuated in an emergency then emergency services should enact that. OPA hopes a similar practice is replicated across all Australian jurisdictions.

6.2. Investigations

VCAT may refer a matter for investigation to OPA where VCAT considers it has insufficient information for the member to make a decision on how to proceed. These matters are dealt with by OPA's Investigations team. During the pandemic, there has been more demand for this role as the VCAT member has had more difficulty in getting the information they need during the normal course of a hearing: difficulties reaching interested parties and other technological hurdles, and the added confusion of telephone hearings discussed above all contribute to this.

This highlights the difficulties seen across OPA and other safeguarding organisations in relation to information flows from and to people with cognitive impairment which are further exacerbated by limits on face-to-face contact.

6.3. Medical treatment decisions

With fewer people attending health care settings and hospitals for non-emergency reasons, this team had fewer matters to consider during the pandemic. During this period they worked with the legal team to develop guidance on consent laws, especially consent around COVID-19 related testing under different circumstances.

OPA is concerned that consent laws may be disregarded during the perceived time pressures and fears of a public health emergency. For example, OPA is aware of forms going out to supporters and substitute decision-makers of people living in aged care facilities that seek pre-emptive consent for coronavirus testing. These forms do not meet legislative requirements around medical decision making and consent.

One thing noted by OPA's Medical Treatment Decisions team during the few weeks Melbourne spent out of 'lockdown' between the start of April 2020 and the end of July 2020, was the rise in the number of urgent and emergency health matters during this time. With people avoiding attending health care setting to 'make room' for people with COVID-19, it is very likely that less timely diagnoses occurred and directly precipitated this growth in urgent medical procedures and decisions. OPA notes public statements were made on this matter as the pandemic progressed and the above evidence came to light.

Recommendation 15

During a long-running public emergency, Australian, state and territory health departments should communicate to the public the importance of monitoring and responding to their non-pandemic related health concerns in a timely manner.

6.4. OPA Volunteer Programs

The experiences of OPA's various volunteer programs have informed many of the issues raised already in this submission: including 'front door' problems and the particular vulnerability of people living in congregate care settings during a pandemic. This section seeks to highlight the safeguarding challenges that have arisen during the pandemic and how the programs have responded.

Before discussing how the program sought to meet these challenges OPA starts by acknowledging that the majority of OPA's volunteers are over 50 years of age. OPA is concerned that many volunteers may leave the program as the risks of COVID-19 will remain in the community until the development and distribution of a vaccine (or effective treatment). This will be an issue for all safeguarding programs that rely on volunteers.

OPA programs have pro-actively sought alternative safeguarding arrangements. The Community Visitors Program trialled and implemented a process for telephone visits to Supported Residential Services (the settings which have been of significant concern during the pandemic) and have also commenced video visits with disability residential services and eligible Specialist Disability Accommodation settings. Both of these initiatives have involved huge logistical challenges and rapid upskilling of staff and volunteers who have

previously worked face-to-face and predominantly with paper reports. The learnings gathered by remote safeguarding (across all OPA program areas) during the pandemic will work well to supplement face-to-face visits when they are reinstated.

Recommendation 16

State and Territory Governments and the NDIS Quality and Safeguards Commission should work collaboratively to explore how safeguards for residents in congregate care can be supplemented during long-running public health emergencies.

The Commission may be interested to learn about the very different experiences of two of OPA's justice related volunteer programs during the pandemic: the Independent Third Person (ITP) program and the Corrections Independent Support Officers (CISO) program. The ITP program, which involves volunteers supporting people with disability in police interviews, was providing over-the-phone support within 72 hours of ceasing face-to-face attendance at interviews. Program staff report that police were actively encouraging them to come up with a way to continue their rights safeguarding functions following the program's decision to stop face-to-face attendance due to virus transmission risks. OPA highlights that while the role of the ITP is not yet mandated by legislation, as we would want, that it is referenced in Police Standing Orders, which likely helped establish the program as an essential procedural safeguard for people with cognitive impairment.

OPA compares this experience, of pro-active police engagement with ITPs and interview numbers at comparable levels and station coverage to pre-pandemic, with that of the CISO program.

CISO program staff contacted prisons and told them that a phone-based service was being offered, with an OPA staff member trained and ready to attend prison disciplinary hearings. In the four months since the program ceased in-person services, no use has been made by prisons of the phone service. Instead, every week on Friday the program is emailed a list of all the prisoners who have declined a CISO. Prior to the pandemic, a CISO attended one prison once a week during the regular hearing times. The CISO would ask the person about to attend the hearing if they would like support and mostly the person would say yes. Program staff are concerned that no one has accepted the offer of a CISO and wonder whether the benefits of the service is being adequately explained to prisoners.

Unlike the ITP program which is referenced in Police Standing Orders, the CISO program is not encouraged by prison operational frameworks. OPA suggests that these examples clearly highlight the benefit of embedding safeguarding programs into policy and legislation, and the risks (especially during an emergency) of not doing so.

Recommendation 17

Corrections Victoria should ensure that the rights protections of the CISO program are embedded in policy and in prison contracts.

Recommendation 18

The Commission should recommend that, wherever possible, safeguarding programs for people with disability be embedded in legislation and government contracts.

OPA notes that, prior to the second Melbourne lockdown, select ITP staff were preparing to once again attend VARE interviews in-person due to the importance of these interviews in criminal justice processes and the benefits to the victim with disability of being supported in giving their evidence. This decision is an example of balancing the 'do no harm' principle while being aware of the adverse consequences of not attending in person.

6.5. Disability Act Officers

OPA's Disability Act Officers have an oversight and advocacy role in Supervised Treatment Order matters (a civil detention scheme regulated by the Victorian Disability Act 2006). While the details of these matters cannot be shared, VCAT hearings for reviews of these matters during the pandemic have raised many of the concerns discussed above. In addition, Officers have been concerned that changes to treatment plans have occurred that were not notified to the Senior Practitioner, OPA or to VCAT on the grounds that the pandemic and related restrictions prevented particular activities from occurring. OPA is concerned that at least some of these changes have been more restrictive than those required by the CHO directions. OPA is also concerned that the residential services involved appeared, in some cases, to have given little thought to how other essential services, supports and routine activities could be facilitated while ensuring compliance with CHO directions.

Disability Act Officer's sought to highlight these concerns during VCAT hearings and advocate for better outcomes for those effected.

6.6. Advice service

Calls to OPA's advice service during the pandemic (and, although fewer, during the fires) have highlighted many of the themes that have been discussed above. Members of the public, including families, friends and disability service provider staff, have contacted the advice service with deeply held concerns for the wellbeing and safety of people with disability living in private homes and congregate care settings. Members of the public have also called with questions about 'front door' policies and to share the impacts of those policies on people with disability. Answering those questions was more difficult during the first Victoria-wide lockdown due to the lack of clarity in the wording of the CHO directions (discussed above); hopefully, the greater specificity of the second Greater Melbourne lockdown directions will enable the advice service to give more comprehensive advice.

OPA has long held that there is a gap in the adult safeguarding framework in Victoria: that there is no clear pathway for investigating safety concerns held for people living in private homes that do not involve a crime or an emergency. Calls during the pandemic reflected this fact: that with the usual community and health services reducing their face-to-face presence, families and advocates held sometimes grave fears for people's safety. Police were often able to do welfare checks on these people, but police are not well-placed to identify abusive or exploitative situations where the person involved has a cognitive impairment and there is no obvious recent physical harm.

Where the Advice Service was able to refer matters to OPA's Community Visitors program or its Disability Act Officers they did, with three-fold growth in these types of referrals.

6.7. The towers

While OPA did not have any clients living in the nine public housing towers that were subject to the most severe lockdown conditions that have occurred anywhere in Australia so far, we did play a brief advocacy role in one troubling situation at the request of a disability advocacy organisation.

OPA would like to highlight the concerns raised by multiple advocacy, community legal organisations and community groups about the circumstances and emergency responses that characterised that initial event and the five days that followed.

The 'hard lockdown' was announced without warning in a press conference and with significant police presence already onsite. The 'hard lockdown' was aimed at stopping further community spread (inside and outside of the towers) in light of the number of cases identified across those two groups of towers, and the close quarters and shared facilities that residents lived with. The public health advice effectively considered all residents potential 'close contacts' of positive cases, and put them into five days of lockdown so tests of residents could be undertaken. OPA does not disagree with the public health advice. OPA would just highlight the fact that it was the overcrowded, poorly maintained living conditions (with reportedly only one lift regularly in operation to service whole buildings) and shared laundries that resulted in entire towers full of people being considered each other's 'close contacts'. These living conditions necessitated much harsher lockdown conditions, and the mental health trauma that can result, than would have been necessary in privately owned tower blocks: with individual laundry facilities, multiple working lifts and fewer apartments per floor. This is another example of the disproportionate impact of the pandemic on already disadvantaged people.

While OPA would not expect the 'do no harm' principle to define the extent of a public health response aimed at preventing further spread of a virus, the implementation of the necessary restrictions should have been sensitive to mitigating the impacts of these orders on already vulnerable people. To this end, the hard lockdown should have been carried out with a reduced police presence and a much greater role for social workers, mental health professionals, community leaders and interpreters. We know, and it has been widely reported, that some people did not have adequate food during the first days of the lockdown, that others did not have urgently needed medication nor in-person access to mental health or nursing supports.

Recommendation 19

State and Territory Governments should invest more in public housing and ensure that it meets generally accepted community living standards.

Recommendation 20

State and Territory Governments should invest more in social programs to support and build strong relationships with public housing residents.

OPA supports the statement made by Victorian Council of Social Services CEO Emma King in response to the conditions of the tower lockdowns, acknowledging that 'high-density living can be a potential incubator for COVID-19', and how to do them better in future.

This is available to download from <https://vcoss.org.au/analysis/hard-lockdowns-things-to-consider/>.

OPA also recommends that the Royal Commission keep abreast of any reports and findings that come out of the recently opened investigation announced Victorian Ombudsman into the 14-day hard lockdown of the tower at 33 Alfred Street, North Melbourne. The Ombudsman said:

I recognise this is an unprecedented global health emergency and governments must act swiftly to protect human lives. People on the front line are doing an extraordinary job to respond to this crisis and help keep us safe.

However, there are lessons to be learnt in how governments can do that in a way that protects people's human rights, including access to fresh air, exercise and medical supplies.²³

Recommendation 21

The Royal Commission should consider recommendations made by the Victorian Ombudsman following her investigation into the tower lockdown, as they come to light.

7. Planning for a health system resources crisis

Like many disability advocacy organisations, early in the pandemic OPA became concerned that if COVID-19 spread widely in the Australian community, our health system would become overwhelmed by people with COVID-19 requiring acute care. At this time distressing scenes were coming out of Italy: of exhausted doctors, overcrowded hospitals and hospital policies that were limiting access to ventilators based on age. Thankfully, Australian hospitals have not yet had to face such difficult choices. However, at the final time of writing, it is clear the dramatic increase of COVID-19 infections in people living in aged care facilities has challenges the capacity of the public hospital system, necessitating the cooperation of private hospitals.

Publishing plans to address such an event would help allay fears of people with disability that they would be forgotten during a public health disaster. And, of course, all prevention and mitigation strategies to avert such a scenario should also be put in place.

Following on from a number of statements of concern from organisations in the sector,²⁴ including that of the Royal Commission, OPA published a position statement titled "An ethical framework for promoting the health of people with disability during the COVID-19 pandemic". The statement is attached to this submission (Attachment A). Points two to five of the statement are particularly relevant to the planning and responses needed to best manage a health system resources crisis and will expand on these points below.

²³ Ombudsman (Vic), 'Ombudsman announces investigation into treatment of public housing tenants in lockdown', Media Release, 17 July 2020, <https://www.ombudsman.vic.gov.au/our-impact/news/ombudsman-announces-investigation-into-treatment-of-public-housing-tenants-in-lockdown/>

²⁴ AFDO, *Statement of Concern, COVID-19: Human Rights, Disability and Ethical Decision-Making* (2020) https://www.afdo.org.au/wp-content/uploads/2020/04/Statement-of-Concern-COVID-19-Human-rights-disability-and-ethical-decision-making_Final.pdf

7.1. The impact of ‘disaster ethics’

After our endorsement of the importance and relevance of a human-rights framework for health-related decision-making, OPA notes ‘that a medical resources crisis would result in the need for additional guiding principles, including one that is not usually present in medical treatment decision-making’:

A health system crisis sees a completely new ethical principle enter the frame, one which does not, and should not, normally apply to medical decision-making. Extreme resource scarcity creates resource allocation decisions that are universally acknowledged as difficult and challenging and without a clear moral answer. Ethical responses to this scenario seek to achieve the ‘greatest good’ with the resources that are available, acknowledging that ‘business as usual’ will result in a greater number of deaths overall and so should be avoided.

Hence, during such a crisis OPA supports an alternative but complementary set of ethical principles: fairness, duty to care, duty to steward resources, transparency, consistency, proportionality and accountability...

We know that in the absence of a medical resource crisis, doctors decide to offer treatment to patients who are likely to benefit from that treatment, only drawing the line at futile or burdensome treatment. A resources crisis would mean that patients who may have benefited from treatment, and recovered, will not always be able to be treated, and may die.

The decisions about scarce resource allocation that occur in disaster scenarios are properly those that seek to achieve the ‘greatest good’. This places people with disability, including many older people, at great disadvantage as the use of limited resources is directed to those most likely to recover well and in a timely manner (with the aid of the resource). This is because the lives of people with underlying health conditions will, in general, take more time and resources to save. OPA further notes that:

[d]etermining ‘a good quality of life’ has a subjective component, and this bias can reduce access to medical treatment for people with disability (especially for people with cognitive impairment) even in non-crisis periods. This bias will be much more dangerous in a time and resource-pressured situation.

This is clearly yet another way in which already disadvantaged people are further disadvantaged and put at risk by a pandemic.

7.2. Implementing ‘disaster ethics’

The world has seen the toll that implementing ‘disaster ethics’ has already taken on doctors and nurses during the pandemic. The *New York Times* recently reported on the life and suicide of a New York doctor who suffered a breakdown after her hospital was overwhelmed by people she couldn’t save.²⁵ While many hospital staff who experience these ‘disaster’ scenarios will likely suffer Post-Traumatic Stress Disorder, regardless of

²⁵ Corina Knoll, Ali Watkins and Michael Rothfeld, “‘I Couldn’t Do Anything’: the Virus and an E.R. Doctor’s Suicide”, (11 July 2020) *New York Times*, <https://www.nytimes.com/2020/07/11/nyregion/lorna-breen-suicide-coronavirus.html>

what implementation policies or decision-making frameworks are put in place, there is at least one implementation strategy that would make a positive difference.

Point 5 of OPA's position statement succinctly covers this ground:

5. The state has an ethical obligation to avoid front-line medical personnel having to make resource-crisis decisions without support.

If the nation's health system is overwhelmed and treating clinicians are left to do their best with the resources they have to hand, not only will they experience moral injury (from making decisions about who should have a chance at life), they may also bring unconscious biases to their decision-making which may disadvantage people with disability.

The state must ensure that, in the event of a resource crisis, an ethical decision-making system is instituted that removes critical resource allocation decisions from the treating team.

Further information on what such a system might look like can be found in plans for such events developed, pre-COVID-19, in the USA. Here a resources crisis is known as a 'crisis standard of care' scenario. A publication of a series of workshops on crisis standards of care summarise the thinking behind the importance of being prepared for such events:

In recent years, a number of federal, state, and local efforts [in the USA] have taken place to develop crisis standards of care protocols and policies for use in conditions of overwhelming resource scarcity. Those involved in these efforts have begun to carefully consider these difficult issues and to develop plans that are ethical, consistent with the community's values, and implementable during a crisis. These planning efforts are essential because, absent careful planning, there is enormous potential for confusion, chaos, and flawed decision making in a catastrophic public health emergency or disaster.²⁶

This paragraph demonstrates the key role community values and buy-in play in the success of such strategies, and the implications of being unprepared.

A potential operational framework for OPA's recommendation above, that critical resource allocation decisions should be removed from the treating team (enabling them to advocate for their patients to the decision-makers), is detailed in section three of the 2010 paper: 'Meeting The Challenge Of Pandemic Influenza: Ethical Guidance For Leaders And Health Care Professionals In The Veterans Health Administration'.²⁷ This document advises the establishment of a Scarce Resources Allocation (SRA) Team (prior to any emergency), noting that:

In a context of increasing scarcity of resources, [activating] the [SRA] team provides a structure for addressing the inevitable tensions that arise between clinicians'

²⁶ Clare Stroud, Bruce M. Altevogt, Lori Nadig, and Matthew Hougan, *Crisis Standards of Care: Summary of a Workshop Series* (2010) Institute of Medicine, <http://www.nap.edu/catalog/12787.html>

²⁷ The Pandemic Influenza Ethics Initiative Work Group Of The Veterans Health Administration's National Center For Ethics In Health Care, 'Meeting The Challenge Of Pandemic Influenza: Ethical Guidance For Leaders And Health Care Professionals In The Veterans Health Administration' (2010) https://www.ethics.va.gov/docs/policy/meeting_the_challenge_of_pan_flu_ethical_guidance_vha_2010_web_posting_2013.pdf.

professional commitment to individual patients and the simultaneous goal of maximizing the survivability of the greatest numbers of persons.²⁸

Further details of this team, including membership and roles, can be found in Attachment B.

Recommendation 22

Australian, State and Territory Health Departments should mandate the creation of Scarce Allocation Resource Teams in hospitals across the country in preparation for a health system resources crisis.

²⁸ Ibid 27.

8. Attachment A: OPA Position Statement

1. OPA endorses the use of human rights-based frameworks for decision-making, highlighting the importance of supported decision-making principles and practices.

OPA recommends the six ethical principles for decision-making developed by leading Australian experts and published in their statement of concern, [COVID-19: Human Rights, Disability and Ethical Decision-Making](#).

OPA notes that it may not always be possible to attain the “free and informed consent of the person with disability” for medical treatment where they have a cognitive impairment. Hence, OPA adds to this framework the importance of following established supported decision-making principles and practices in circumstances where obtaining a person’s free and informed consent without support is not possible.

2. OPA notes that a medical resources crisis would result in the need for additional guiding principles, including one that is not usually present in medical treatment decision-making.

A health system crisis sees a completely new ethical principle enter the frame, one which does not, and should not, normally apply to medical decision-making. Extreme resource scarcity creates resource allocation decisions that are universally acknowledged as difficult and challenging and without a clear moral answer. Ethical responses to this scenario seek to achieve the ‘greatest good’ with the resources that are available, acknowledging that ‘business as usual’ will result in a greater number of deaths overall and so should be avoided.

Hence, during such a crisis OPA supports an alternative but complementary set of ethical principles: fairness, duty to care, duty to steward resources, transparency, consistency, proportionality and accountability. Noting that the fairness principle incorporates the disability-specific principles outlined above.

3. OPA acknowledges the additional and disproportionate risks of health system crisis for people with disability and older people.

While COVID-19 already is known for the greater toll it takes on the elderly and people with comorbidities^[1], OPA notes that determining ‘a good quality of life’ has a subjective component, and this bias can reduce access to medical treatment for people with disability (especially for people with cognitive impairment) even in non-crisis periods. This bias will be much more dangerous in a time and resource-pressured situation.

4. The state has an ethical obligation to avoid having to make ‘crisis’ decisions by implementing preparation and mitigation strategies.

In working together to flatten the curve of the pandemic trajectory and prepare for potential spikes in COVID-19 cases, Australia’s Federal, State and Territory governments have successfully met this ethical obligation to the population. OPA hopes the governments of Australia can continue to be successful in this.

5. The state has an ethical obligation to avoid front-line medical personnel having to make resource-crisis decisions without support.

If the nation’s health system is overwhelmed and treating clinicians are left to do their best with the resources they have to hand, not only will they experience moral injury (from making decisions about who should have a chance at life), they may also bring unconscious biases to their decision-making which may disadvantage people with disability.

The state must ensure that, in the event of a resource crisis, an ethical decision-making system is instituted that removes critical resource allocation decisions from the treating team.

6. The state has an ethical obligation to mitigate the impacts of overarching public health strategies on the wellbeing of vulnerable groups.

When strategies are devised to protect the population as a whole, those laws and policies will likely have unintended consequences for people with disability. The state must consider the implications of COVID-related strategies for people with disability and older people (as well as other known disadvantaged groups) and act to mitigate negative impacts.

7. The state has an ethical obligation to proactively target resources to prevent COVID-19 outbreaks among vulnerable groups.

More can be done in Australia to proactively target resources to prevent COVID-19 outbreaks among vulnerable groups, particularly those experiencing the dual threat of comorbidity or advanced age and congregate living. To date, Australia's prevention strategies have focused on the health system; there is good reason now to expand those strategies to encompass aged care facilities and congregate care for people with disability (who often have comorbidities).

8. The state has an ethical obligation to respond to outbreaks in congregate care settings.

Given the risks COVID-19 poses in congregate care settings, the state should be ready to respond to suspected and actual outbreaks with appropriate supports and resources.

9. Attachment B: Scarce Resource Allocation (SRA) Team and Triage Team Membership and Roles²⁹

Scarce Resource Allocation Team Leader. The SRA team leader should have broad-based knowledge of the resources and capabilities of the health care organization. The team leader must possess situational awareness -the ability to acquire and act on knowledge as the pandemic unfolds in a manner that is consistent with the health care organization's mission and ethical tenets. The team leader should be an experienced and respected member of the health care organization staff with proven leadership skills and a top-to-bottom understanding of the health care organization's strengths, reserves, and limitations. The team leader should have final responsibility for and authority over clinical decisions that involve triage and scarce resource allocation including, in consultation with the Triage Team, monitoring the event specific, real-time epidemiologic data to determine whether and how the assessment tools in the tertiary triage protocol should be adjusted. Throughout the public health emergency, the team leader should report to the Facility Director and chief of staff or designee, as appropriate within the Incident Command structure.

Logistics/Management Representative. A representative of the health care organization's management team should provide guidance on the capabilities of the organization with respect to resources, personnel, and external support. This person should have knowledge of logistics related to the acquisition and distribution of critical supplies, security, fiscal matters, internal and external communication, control of patient information, and cooperative capabilities with other health care organizations. The management representative may also report to a larger Emergency Operations Committee responsible for directing the organization's overall response to pandemic influenza.

Ethics Representative. A member of the organization's Integrated Ethics program, generally from the Ethics Consultation Service, should provide guidance to resolving ethical conflicts, disputes, and dilemmas. This person should have knowledge of widely accepted ethical principles and the special ethical challenges that community medical disasters and public health emergencies present. This person should ensure that ethical values are an integral part of any decision process.

Critical Care Medicine Representative. A physician with expertise in critical care medicine should provide guidance about the management of intensive medical care and proposed implementation of crisis standards of care.

Nursing Representative. The Nurse Executive or other designated nurse leader should provide information about nurse staffing capacity to meet additional health care service needs of patients. Nursing judgments must be reflected in the SRA team's decisions to alter standards of care that result in the nursing staff performing duties that are normally performed by physicians, in the modification of nurse-patient ratios, and in decisions to include nonclinical staff in clinical support roles.

Emergency Department Representative. This role should be filled by a nurse or physician who is capable of providing real-time information about surge capacity and clinical decision-making in the emergency department.

Infectious Diseases Representative. An infectious diseases physician or infection control specialist should provide regular updates regarding the status and impact of the pandemic and the management of patients with influenza.

Palliative Medicine Representative. A physician with experience in palliative medicine should provide updates on the demands for palliative care and strategies to meet these demands. A qualified physician assistant or nurse practitioner may fill this role when a qualified physician is not available.

²⁹ Ibid 28-29.

Social Work Representative. A licensed clinical social worker should provide updates on the social service demands imposed on the health care organization as a consequence of pandemic influenza.

Chaplain Representative. A chaplain should provide regular updates on the capacity of the health care organization to address the special spiritual needs of patients and family members, especially of those patients a physician deemed ineligible to receive care that would normally be delivered.

Patient/Veteran or VSO Representative. A representative of the Veteran community can provide specific insight on Veterans' issues and help to ensure transparency in the functioning of the team. Ad Hoc Representatives from Other Departments. Representatives from other departments significantly affected by the pandemic may be necessary to provide updates on their capacity to meet surge demands for care – for example, an engineering representative who can advise on available supplies of oxygen and utilities.

Triage Team Membership and Roles

A group functioning under the direction of the SRA team, the Triage Team, should be designated and is responsible for tertiary triage scoring and decisions based on the tertiary triage protocol and available resources. Membership of the Triage Team includes, at minimum, a critical care medicine, nursing, and logistics/management representative. The Triage Team will consider regional and local circumstances and the resources available, and use the triage protocol to determine which patients are eligible for life-saving resources. Although the Triage Team functions under the direction of the SRA, the Triage Team's role within the SRA should, ideally, be limited to triage implementation, that is, collecting data, ensuring its accuracy, and directing bedside clinicians on triage decisions.