ADACAS Submission to the Royal Commission into Aged Care Quality and Safety (July 2020)

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1. About ADACAS

The ACT Disability Aged and Carer Advocacy Service (ADACAS) has been providing advocacy for and with people with disability, older people, people with mental health issues and carers for 29 years. We are based in Canberra, and work with clients in both the ACT and set zones in the Shoalhaven and Eurobodalla areas of NSW. As an advocacy service, ADACAS is frequently working with people who are "falling through the cracks" in current service systems. We additionally offer support coordination to a small number of NDIS participants, and have a Projects/research team, which has specific expertise in Supported Decision Making (SDM) and its application to healthcare and also its use in the context of older persons abuse. In 2019 ADACAS launched its SDM elder abuse app for android phones and is working with Apple to have this available, free, in I-phones.

Throughout this submission we seek to highlight the issues that our clients have raised with us, and will use case studies to demonstrate circumstances that have occurred. We value the opportunity to make comment on what can be improved.

ADACAS acknowledges the traditional owners of the various lands on which we work: the Ngunnawal communities for our work in the Canberra area, the peoples from Tharawal and Yuin communities for our work across on the South Coast), and pay our respects to their Elders, and to all Aboriginal and Torres Strait Islanders in our communities.

2. General statement about Aged Care Quality and Safety

There are some issues that are intrinsic to our sense of who we are as a community, which speak to our humanity as a society and, at times, our lack thereof. The Royal Commission into Aged Care Quality and Safety's Interim Report has spoken of a "shocking tale of neglect"[1] which pervades the aged care system, from its broad administration and funding of individuals in need of care and support, to the delivery of that care within aged care facilities. The Report has reinforced the experience and observations of ADACAS staff who have worked with older people in aged care settings over many years. These observations have included:

- The lack of timely access to the aged care system, particularly for those who wish to remain living at home, even when the need has been assessed as immediate and urgent.
- The lack of "time" that is able to be spent with older people in settings, because staffing levels are, in our view, inadequate, with the result that "care" becomes just tending to the bare necessities of life rather than the qualitative experience of being with people and sharing human contact.

[1] Royal Commission into Aged Care Quality and Safety 2019, *Interim Report: Neglect Volume 1*, Commonwealth of Australia, p. 1

- The lack of training in skills beyond basic personal care, although it must be said there are some excellent staff working across both residential and home-based aged care. The failure to apply a system-wide accredited workforce training regime that emphasises emotional and psychological supports as well as personal and health care has contributed to this, as has the poor level of pay attributed to workers in the industry. This lack of attention to the frontline workforce speaks to a systematic neglect of the aged care sector and sends a very worrying message about the value of that work and of the clients who are recipients of the care and support.
- The difficulty that residents of residential aged care facilities (RACFs) have in accessing quality healthcare, and the shocking and preventable deaths that occur due to negligence within RACFs and policies of both aged care and healthcare providers that place unnecessary obstacles in the way of residents accessing general and specialist healthcare that is equitable with others in our community. In particular we focus on the mental health of residents in these facilities, something that is not addressed adequately at the best of times, but which in COVID-19 has been further sidelined, and which is becoming a further threat facing those who are isolated within the facilities with inadequate access to their loved ones.
- The lack of focus upon human rights, very necessary when considering how we best protect and enhance the lives of our most vulnerable people. To some extent the new Aged Care Standards and the Aged Care Charter of Rights, both launched during the course of the Aged Care Royal Commission in July 2019 have raised awareness of rights, and the role of Advocacy and the Aged Care Quality and Safety Commission in monitoring and educating people about these rights. But the onset of COVID-19 has unfortunately led to behaviour within RACFs that are in breach of these rights, and have a very negative impact on the health and wellbeing of older people living there.

This submission will focus mainly on the key issues that present to our Advocates working daily with older people in the aged care system and their families, and which appear to be entrenched and systemic in nature. Given the submissions already provided to the Royal Commission to date, and the findings that have been reported, the submission will have as its chief focus observations that ADACAS has about how the system may be improved, particularly with a stronger focus upon human rights and the practical and conscious application of these upon all recipients of aged care. At the head of this approach, however, needs to be a system that entitles older people to the aged care they require, similar in principles to the National Disability Insurance Scheme (NDIS) but ideally less administratively complex and restrictive.

3. ADACAS Recommendations

Recommendation 1: that people who need Aged Care home care packages receive packages immediately upon application (rather than waiting via a National Prioritisation Queue).

Recommendation 2: that there be a fifth level of Home Care package offered (in line with the recommendations of David Tune's Legislated Review into Aged Care[2], at a level which does not exceed the level of funding needed to support someone to live in residential aged care.

Recommendation 3: that staffing levels (and the staffing mix) are at a level suitable to be able to respond appropriately (and in a timely way) to all residents' needs, day and night.

Recommendation 4: that all aged care staff are required to have appropriate levels of qualifications for their roles, and that ongoing human rights focussed professional development training and mentoring is made available.

Recommendation 5: that a more specific definition of definition of restrictive practices be recommended – ideally one which aligns and expands on the one that is used by the NDIS, perhaps the one used by the ACT Senior Practitioner, thus including Seclusion, Physical Restraint, Mechanical Restraint, Chemical Restraint and Environmental Restraint and Verbal directions or gestural conduct of a coercive nature.

Recommendation 6: that restrictive practices is regulated nationally for the Aged Care sector (residential aged care and home care and other services) with the aim of reducing with a view to eliminating restraint, seclusion and restrictive practices and that significant penalties are introduced for misuse of seclusion or restraint, to assist with achieving this aim.

Recommendation 7: that the principle (embedded in the Senior Practitioners Act 2018) also be adopted and legislated nationally for aged care service providers– i.e. that "service providers should also only use restrictive practices in very limited circumstances – as a last resort, in the least restrictive way and for the shortest period possible in the circumstances"[3].

Recommendation 8: that the Senior Practitioner (in the ACT) and equivalent roles in other states and territories have their powers expanded such that they can provide monitoring and oversight of efforts to reduce and eliminate restrictive practices for people receiving aged care services.

Recommendation 9: We recommend that the Official Visitor scheme be expanded such that it can cover aged care services, as an additional adjunct to the Serious Incident Response Scheme, and other monitoring schemes and mechanisms being put in place.

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[2] Commonwealth of Australia Department of Health (2017) *Legislated Review of Aged Care 2017*. Accessed via: https://www.health.gov.au/resources/publications/legislated-review-of-aged-care-2017-report in July 2020.

[3] Office of the Senior Practitioner (2018), *ACT Senior Practitioner website*, accessed via https://www.communityservices.act.gov.au/quality-complaints-and-regulation/office-of-the-senior-practitioner in July 2020.

Recommendation 10: That high-quality mental health support is urgently made available to people living in residential aged care at a level that meets the needs of all people experiencing mental ill health whilst living in residential aged care (including people who experience disability).

Recommendation 11: That there is adequate support and funding made available to ensure that the environment and experience of living in residential aged care facilities is conducive to good mental health for all residents (i.e. not solely to remedy the negative, but is actively promoting good mental health).

Recommendation 12: That mental health support programs adopted in support of people living in residential aged care allow for tailored solutions which are co-designed in partnership with people living in each of the residential aged care settings.

Recommendation 13: That in the interests of older people regaining choice and control and also specialised services being equitably available for those that require them: that mental health care and support programs available to people living in the community, are also made equitably available to people living in residential aged care such that people can access the service that suits their needs best and that any additional barriers to access to these services being experienced by older people living in community or residential aged care (e.g. finances, transport, access to staff support to attend etc) are urgently addressed and remedied.

Recommendation 14: That welfare and pastoral care support be additionally made systemically available at the level required in all residential aged care facilities to meet the needs of residents. That the design and approach to this support be co-designed with older people living at each residential aged care facility.

Recommendation 15: That access to and roles of the Community Visitor Scheme be expanded.

Recommendation 16: That there are urgent provisions made for appropriate levels of physical and mental health support and to safeguard the health and wellbeing of people living in residential aged care during the COVID-19 pandemic (and with any future infectious outbreaks).

Recommendation 17: That connections to families, friends and community are prioritised, and visits permitted in person to the extent that it is safely possible, and when not safe in person, that support and digital devices be made available such that people can connect via phone or video-chat.

Recommendation 18: That there are phone and digital solutions (tablets, computers, phones) urgently made available to support people being able to continue some contact with family and friends in situations where in person visits are not as possible, (and staff made available to support people to be able to use them as needed).

Recommendation 19: The Royal Commission needs to look at how facilities should run in order to facilitate best practice in SDM, and not rush to judgements on staffing and funding levels without taking into account the need for staff to have adequate time to support decisions when this assistance is wanted or needed (acknowledging that it is a right if people have a disability, for people to have access to this support).

4. Responses on Specific Topics

4.1. The Right to Aged Care

As the Australian population ages and people expect to live much longer than has been the norm in the past, the experience of living with some form of disability and/or health condition will become very common and the demand for care and support will increase. This realisation has been at the heart of the *Living Longer Living Better*[4] reforms of 2011 and of subsequent aged care policies, including consumer-directed care and the achievement of wellness and reablement in the delivery of support and care to older people. What has been missing is an entitlement to this care, at the time it is needed.

The lack of entitlement has led to a significant queue of people waiting for the care they have been assessed as needing at the point of assessment, with the result that, as is widely reported, people have died waiting, but at the very least the condition of an eligible person has deteriorated by the time their support is able to be provided

A bolder vision is required, that places the rights of older people at its centre, and builds a system that is fit for purpose to provide quality aged care supports is imperative. **ADACAS believes that the bold vision for legislative, policy and service reform in Australia needs to be back up by support for a United Nations Convention on the Rights of Older Persons[5], and that in light of the tragic impact of COVID-19 upon older people, the Australian Government should show leadership to bring such a convention about.**

4.2. Home Care

A revised aged care system must embed an entitlement to aged care support, when it is needed and to the extent it is needed. Nowhere is this more evident than in the wait for support for older people at home.

People who need home care packages need access to them immediately, not to have to wait in a queue. We emphasise, as has been reported already to this Royal Commission: that delays in access to the necessary levels of support via aged care packages puts people under enormous stress and means that situations can deteriorate, resulting in premature hospitalisation, premature entry to residential aged care and in deaths[6]. People on low incomes are disproportionately affected by delays, as they can't pay for private assistance during the "waiting period".

There are issues with the quality and remuneration of staff providing home care, which are addressed below at 4.3.3.

[4] See https://apo.org.au/node/29086

[5] See https://humanrights.gov.au/about/news/speeches/un-convention-rights-older-persons

[6] Royal Commission into Aged Care Quality and Safety (2019), *In the Matter of the Royal Commission into Aged Care Quality and Safety: Transcript of Proceedings: Adelaide 22 March 2019 Commonwealth of Australia*, Page 1098. Accessed via: https://agedcare.royalcommission.gov.au/media/12051 in July 2020.

Recommendation 1: that people who need Aged Care home care packages receive packages immediately upon application (rather than waiting via a National Prioritisation Queue).

Recommendation 2: that there be a fifth level of Home Care package offered (in line with the recommendations of David Tune's Legislated Review into Aged Care[7], at a level which does not exceed the level of funding needed to support someone to live in residential aged care.

4.3. Residential Aged Care Services

As an advocacy service which regularly visits all of the aged care facilities in the ACT, there are many common themes that we hear from residents and their families:

4.3.1. Number of staff / time available

Clients consistently tell us: "*there are just not enough staff"* or *"the staff don't have the time to talk with us"*. Every resident deserves adequate care and support. When people have more complex needs, staffing needs to be increased accordingly such that everyone's needs can be met. ADACAS recognises that the problem of adequate staffing requires a broad discussion about funding levels that are directed at the crucial job of working in person with vulnerable and frail older people in these facilities, and that this discussion needs to involve government funding bodies as well as providers, and also needs to take seriously the level of pay that is accorded to those at the frontline who do the most important work.

From an adult daughter carer:

I love my Mum dearly. She used to be a nurse, and spent her life caring for others, but Mum can no longer feed herself – I attend the aged care facility where she lives, every day to assist her with meals. When I don't attend, the staff put the food on the table by her bed, but Mum can't feed herself. They know this, but some of the staff still don't help. On one day recently when I couldn't be there - Mum was so hungry, and when the staff member didn't stop to help, she tried to feed herself, but knocked the plate by accident, and then the staff yelled at her for making a mess. She has said to me that it is too much for her to have them yell. Some staff are good – they realise and take the little bit of extra time to feed her – but others don't. I've reported the issues again and again – but now they just see me as a troublemaker, and don't listen to my feedback. My Mum is only in care as after Dad died, she needed more support than I could give – but I am so terrified that something awful will happen if I don't get there multiple times each day, that it is almost more care than when she stayed with me. Mum is sad all the time since moving into care. She keeps telling me now that she wants to die, when before she loved life, and catching up with her friends and family. She sobs and sobs and sobs "what did I do to deserve this hell?". I try the best I can to make it better, but it is so very distressing.

[7] Commonwealth of Australia Department of Health (2017) *Legislated Review of Aged Care 2017*. Accessed via: https://www.health.gov.au/resources/publications/legislated-review-of-aged-care-2017-report in July 2020.

Zindo (not his real name) is 89 years old. He recently went outside the aged care facility in which he lives, for a breath of fresh air (at approx. 7:30pm), but accidentally had forgotten to take his keys/pass with him. He does not have a mobile phone. He knocked periodically at all the various doors, but could not rouse any staff. He was very exhausted, and scared. He remained locked outside, in the gardens all night: no-one realised he was missing until about 8am the next morning, by which time he was wet through, dehydrated, very distressed, and his health had considerably deteriorated.

A nurse from an aged care facility told us: I am often the only nurse on duty. I (along with four carers who are not medically qualified) am then responsible for supporting the health of 120 people, many of whom have very complex/high level health needs. It is not safe. It is not sufficient to allow us to meet people's needs. It means that care is not being given in a timely manner. It means pain relief is not given in a timely manner. Especially for people with dementia. People should not be in agonising pain or have their health deteriorate purely due to inadequate health care related to low staff numbers. It must change. Other staff tell us: some of the care facilities share staff, and try and manage with just the one nurse on call for up to four different facilities. It is completely inadequate. Overnights in particular are the worst.

Recommendation 3: that staffing levels (and the staffing mix) are at a level suitable to be able to respond appropriately (and in a timely way) to all residents' needs, day and night.

4.3.2. Young people with disability in aged care

The quality of care to younger people in aged care has long been a topic of concern, and the Royal Commission has addressed this. While this strictly is an issue for the National Disability Insurance Scheme (NDIS) to resolve, whilst that scheme takes its time to address this properly the onus is upon the aged care providers, who are now being paid by the NDIS to look after younger people with disability in their facilities, to not only ensure their accommodation and support needs are met, but also facilitate their activities of daily living external to the facility, including community inclusion and therapeutic activities. ADACAS has witnessed obstacles being put in the way of people living in these settings to accessing outside activities, particularly under COVID-19.

Ben (not his real name), a resident of an aged care facility needed assistance via a hoist to access the toilet. As Ben is a larger person, a bariatric hoist (and two-person assist) was required for him to be able to go to the toilet. The facility had only one hoist of this type. It was being shared between two people, who lived on different wings (opposite sides of the facility).

There was usually only one staff member on duty on the wing where Ben lived. Every time Ben needed to go to the toilet, another staff member had to be sourced, and also the hoist obtained. As the staff member on duty in the wing was very busy (as were other staff), sometimes this meant that Ben would soil himself, or be waiting in inadequate continence products for an hour or more.

A second hoist was repeatedly requested of both the NDIS (the person is an NDIS participant living in aged care), and also of the Aged care facility. The NDIS advised that it was the Aged Care facilities concern, the Aged Care facility refused to purchase a second hoist (so that at least the resident did not have to wait. Ben eventually moved entirely to using continence products (which have had a subsequent and very negative impact on his health).

4.3.3. Qualifications/expertise of staff:

It is imperative that all aged care staff have appropriate levels of qualifications for their roles. There is additionally a need for increased initial training on human rights, working with vulnerable people, on eliminating restraint and seclusion, on quality standards, on quality care for people with dementia. Ongoing professional development for staff (and mentoring to encourage culture change) should also continue in these areas. The Aged Care Standards, in particular Standard 1, offer significant training opportunities for staff in understanding what client-centred care and support is about, and lends themselves to a rights approach.

The COVID-19 outbreak has highlighted a dearth of training on how to handle such a situation, and the lack of application of the recommendations from the Pollaers report[8] on a workforce strategy for the sector has left it and its clients vulnerable at the time that great expertise was needed.

Comments were provided by a recipient of home-based aged care, in relation to the quality, skills and confidence of staff who provide support on a daily basis. There is an additional skill set required for staff who work with people in their own homes, to enable them to do very personal tasks for people in such a way as to ensure the choice and control of their clients. This is of course required of staff in residential settings too, to foster the sense of home within RACFs, and to maintain the agency of individual clients. But these skills appear to be lacking, nor is there much invested in staff in any aged care setting, with a high degree of casualisation and a very low rate of pay overall for the staff who are involved in the most intimate and important aspects of aged care delivery. We recommend a greater focus on training and qualifications of frontline staff, and recognise that at the same time better remuneration is provided to reflect the skills that are required to confer dignity upon their clients.

Recommendation 4: that all aged care staff are required to have appropriate levels of qualifications for their roles, and that ongoing human rights focussed professional development training and mentoring is made available.

4.3.4. Coercion, Restrictive Practices, Restraints and Seclusion

As evidence already presented to the Royal Commission has shown, restrictive practices, in terms both of seclusion and the many forms of restraint are prevalent

[8] See https://www.health.gov.au/resources/publications/a-matter-of-care-australias-aged-care-workforce-strategy

across the aged care system[9]. Restrictive practices and seclusion have caused immense harm, and the existence of such widespread abuses in these domains speaks to profound and entrenched systemic failures over many years[10].

An older person with dementia, who is living in a residential aged care in an area reserved for people living with dementia, says each visit to (heartbroken family members who were unable to care for their father at home any longer (and tried but couldn't find alternative housing options able to better meet his needs): "Why are you locking me away in this prison? Why?"

The paper on Restrictive practices in Residential Aged Care, that was issued by the Royal Commission in May 2019, was focused on physical and pharmacological restrictive practices[11]. Whist the interim report acknowledged a broader array of restrictive practices in the body of the chapter[12], the definition continued to focus on physical or pharmacological restraint.

This is in contrast to the definitions adopted in other publications and by other agencies:

- the Australian Law Reform Commission (ALRC) report *Equality, Capacity and Disability in Commonwealth Laws (DP 81)* identifies restrictive practices as including restraint (chemical, mechanical, social or physical), and seclusion).
- The NDIS Quality and Safeguards Commission adopted the following categorisation: Seclusion, Physical Restraint, Mechanical Restraint, Chemical Restraint and Environmental Restraint[13] [14].
- In the ACT, the Senior Practitioner Act (2018) recognises seclusion in addition to the following forms of restraint: chemical, environmental, mechanical, physical, and an additional category: verbal directions, or gestural conduct, of a coercive nature, which is defined as "The use of verbal or non-verbal

[9] Royal Commission into Aged Care Quality and Safety (2019), *Interim Report: Neglect*: Volume 1: Chapter 8: Restrictive Practices, Pages 193-216, accessed online via: https://agedcare.royalcommission.gov.au/publications/interim-report in July 2020

[10] Royal Commission into Aged Care Quality and Safety (2019), *Interim Report: Neglect*: Volume 1: Chapter 8: Restrictive Practices, Pages 193-216, accessed online via: https://agedcare.royalcommission.gov.au/publications/interim-report in July 2020

[11] Royal Commission into Aged Care Quality and Safety (2019), *Background Paper 4 – Restrictive practices in residential aged care in Australia*, viewed May 2019 from https://agedcare.royalcommission.gov.au/publications/Pages/default.aspx

[12] Royal Commission into Aged Care Quality and Safety (2019), *Interim Report: Neglect*: Volume 1: Chapter 8: Restrictive Practices, Pages 193-216, accessed online via: https://agedcare.royalcommission.gov.au/publications/interim-report in July 2020

[13] NDIS Quality and Safeguards Commission, Restrictive Practices Authorisation in NSW from 1 July 2018 (Information for NDIS registered service providers, viewed online 20 May 2019 from: https://www.ndiscommission.gov.au/sites/default/files/documents/2018-07/NSW%20-%20Restrictive%20Practice%20Authorisation%20from%201%20July%202018.pdf

[14] NDIS Quality and Safeguards Commission (2020), *NDIS Quality and Safeguards Commission Regulated Restrictive Practices website*, accessed online via https://www.ndiscommission.gov.au/regulated-restrictive-practices in July 2020.

communication that degrades, humiliates or forces a person into a position of powerlessness or a verbal threat that results in a restrictive practice."[15]

In ADACAS' view there is much to be gained by using similar definitions of restrictive practices across the lifespan, and we encourage that at a minimum the categories of the NDIS be adopted, with our preference being the definition used in the ACT Senior Practitioner Act. In the ACT, the Senior Practitioner Act (2018) establishes the role of the Senior Practitioner, which office focuses on seeking to reduce and eliminate the use of restrictive practice and seclusion in the fields of education, disability support and child protection in the ACT. The Senior Practitioners Act (2018) "enshrines the principle that service providers should only use restrictive practices in very limited circumstances, as a last resort, in the least restrictive way and for the shortest period possible in the circumstances"[16]. There are strict protocols around the monitoring of these processes. The combination and approach to the Senior Practitioner role and mandate has proved for powerful changes in disability services, and in our view could do likewise in aged care services – and thus, in our view, the arrangements

Recommendation 5: that a more specific definition of definition of restrictive practices be recommended – ideally one which aligns and expands on the one that is used by the NDIS, perhaps the one used by the ACT Senior Practitioner, thus including Seclusion, Physical Restraint, Mechanical Restraint, Chemical Restraint and Environmental Restraint and Verbal directions or gestural conduct of a coercive nature.

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Recommendation 8: that the Senior Practitioner (in the ACT) and equivalent roles in other states and territories have their powers expanded such that they can provide monitoring and oversight of efforts to reduce and eliminate restrictive practices for people receiving aged care services.

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[15] Office of the Senior Practitioner (2018), *ACT Senior Practitioner Fact Sheet*, viewed May 2019, from https://www.communityservices.act.gov.au/quality-complaints-and-regulation/office-of-the-senior-practitioner/act-senior-practitioner-fact-sheet

[16] Office of the Senior Practitioner (2018), *ACT Senior Practitioner website*, accessed via https://www.communityservices.act.gov.au/quality-complaints-and-regulation/office-of-the-senior-practitioner in July 2020.

[17] Office of the Senior Practitioner (2018), *ACT Senior Practitioner website*, accessed via https://www.communityservices.act.gov.au/quality-complaints-and-regulation/office-of-the-senior-practitioner in July 2020.

4.3.5. Monitoring, Complaints and Quality Assurance

As has been stated emphatically in the Interim Report the aged care system needs fundamental reform[18] and a radical re-imagining to be able to meet the needs of older people. We strongly endorse the direction that the Interim report has taken to date, and support strategies of introducing un-announced checks at residential aged care facilities, noting the importance of this continuing. We also believe there need to be clear avenues and options for reporting concerns, including anonymously, by staff / visitors and other residents.

ADACAS also supported the introduction of a Serious Incident Response Scheme (as earlier recommended by the Australian Law Reform Commission)[19].

To complement this SAR scheme and other monitoring mechanisms – ADACAS would support any supplementation to the Official Visitor scheme, such that Official Visitors can visit aged care facilities to see older residents. We note that this scheme could act as an additional safeguard, in that it may feel easier for older people to access the support of an Official Visitor (and thus to seek assistance earlier – hopefully allowing for earlier intervention before a serious incident occurs).

Recommendation 9: We recommend that the Official Visitor scheme be expanded such that it can cover aged care services, as an additional adjunct to the Serious Incident Response Scheme, and other monitoring schemes and mechanisms being put in place.

4.3.6. Mental ill health and Residential aged care

The prevalence of mental ill health for people living in residential aged care is much higher than in the community at large. The Australian Institute for Health and Welfare (AIHW) reported that of a snapshot of people living in permanent residential aged care on 30 June 2019: "The majority (87%) were diagnosed with at least one mental health or behavioural condition. Almost half (49%) of people in permanent residential aged care had a diagnosis of depression."[20] This can be compared with estimates from Beyond Blue advising that in the broader population of people over the age of 65, that the rate of depression was between 10-15%.[21]

Despite the high rate at which people in residential aged care experience the impacts of mental ill health in practical terms, unless people are able to pay privately, it is our experience that it currently often continues to be extremely difficult for people living in residential aged care to access mental health support (psychologists, social workers, psychiatrists etc).

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[18] Royal Commission into Aged Care Quality and Safety (2019), *Interim Report: Neglect*: Volume 1, accessed online via: https://agedcare.royalcommission.gov.au/publications/interim-report in July 2020

[19] Australian Government Australian Law Reform Commission (ALRC) (2017), *Elder Abuse: A National Legal Response: Final Report*. ALRC Report 131, available online via: https://www.alrc.gov.au/publication/elder-abuse-a-national-legal-response-alrc-report-131/, accessed July 2020

[20] Australian Institute of Health and Welfare (2019), *People's care needs in aged care,* accessed via: https://gen-agedcaredata.gov.au/Topics/Care-needs-in-aged-care in July 2020.

[21] Beyond Blue (2017), *Media Release: Beyond Blue and NHMRC in Landmark research into older Australians*, available online via: https://www.beyondblue.org.au/media/media-releases/media-releases/beyond-blue-and-nhmrc-in-landmark-research-into-older-australians, accessed July 2020

Whilst there are plans to offer mental health support within residential aged care facilities via an Australian government funded Primary Health Network program which is building incrementally with the aim of being eventually available across all residential aged care facilities, in our view, given the limitations of what this program can offer - even after this program is fully rolled out, **much more will be needed** in order to adequately address the depth and complexity of need for high quality health, disability and mental health support.

Many of the older people living in residential aged care experience disability, whether via dementia or via other disabilities, or a combination. The AIHW report examining people's care needs in aged care found that just over half (53%) of people in permanent residential aged care had a diagnosis of dementia[22]. Many of the older people living in residential aged care are living in residential aged care often as a direct result of needing support with high care needs arising from complex ill health and/or disability.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) states that "persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability"[23]. As a signatory to the CRPD, Australia has an obligation to ensure both that there is equitable access to treatment and support for people experiencing mental illness who are also living in residential aged care, but also to ensure that the environment and experience of living in residential aged care facilities is conducive to good mental health for all residents. From the many conversations that ADACAS advocates have had with older people living in aged care, we have concluded that there is a palpable sense of isolation brought about by a lack of social interaction, quality of care concerns, being neglected/feeling alone and forgotten, and a lack of culturally appropriate care, as well as abuse and neglect. We believe that all these issues should be able to be addressed/remediated with the right combination of support and care being made available.

Under Australian discrimination laws, it is not acceptable to discriminate on the grounds of age, or disability. Yet at the present time, one could argue that mental health care is not equitably accessible to older people living in residential aged care. Medical, psychology and social work literature talk of a biopsychosocial-spiritual approach to healthcare, where the various dimensions of a person's experience must be considered in a holistic way as they are intrinsically linked, and cannot be separated[24].

Recommendation 10: That high-quality mental health support is urgently made available to people living in residential aged care at a level that meets the needs of all

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[22] Australian Institute of Health and Welfare (2019), *People's care needs in aged care,* accessed via: https://gen-agedcaredata.gov.au/Topics/Care-needs-in-aged-care in July 2020.

[23] UN General Assembly, *Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly*, 24 January 2007, available via RightsApp (an app issued by the Australian Human Rights Commission which includes full text of the UDHR and ten other major human rights instruments), accessed July 2020.

[24] Sulmasy, Daniel. (2002). *A Biopsychosocial–Spiritual Model for the Care of Patients at the End of Life*. The Gerontologist. 42 Spec No 3. 24-33. 10.1093/geront/42.suppl_3.24. Accessed via https://www.researchgate.net/publication/11050534_A_Biopsychosocial-Spiritual_Model_for_the_Care_of_Patients_at_the_End_of_Life in July 2020.

people experiencing mental ill health whilst living in residential aged care (including people who experience disability).

Recommendation 11: That there is adequate support and funding made available to ensure that the environment and experience of living in residential aged care facilities is conducive to good mental health for all residents (i.e. not solely to remedy the negative, but is actively promoting good mental health).

Recommendation 12: That mental health support programs adopted in support of people living in residential aged care allow for tailored solutions which are co-designed in partnership with people living in each of the residential aged care settings.

Recommendation 13: That in the interests of older people regaining choice and control and also specialised services being equitably available for those that require them: that mental health care and support programs available to people living in the community, are also made equitably available to people living in residential aged care such that people can access the service that suits their needs best and that any additional barriers to access to these services being experienced by older people living in community or residential aged care (e.g. finances, transport, access to staff support to attend etc) are urgently addressed and remedied.

4.3.7. Welfare/Pastoral Care services and mental health

Many people living in residential aged care experience barriers experience isolation and loneliness, and barriers to accessing the community. These can have a very serious and negative impact on mental health and wellbeing:

At the present time the existing systems for support draw lines between informal supports such as friends and family for those who have these supports and:

- routine welfare and pastoral care services which are considered the responsibility of aged care facilities[25] (although for example, the community visitor style programs and sometimes other volunteer efforts are available from NGOs),
- health and mental health care (shared responsibilities through commonwealth and state/territory agencies),
- disability supports (provided in various ways, but not at equitable levels to meet the needs of residents with disability when compared with what is available to the rights of younger people with disability who are NDIS recipients) and
- for those at end of life or in high pain: palliative care services (delivered by healthcare services).

Whilst having services arising from different origins can be a safeguard – these types of services are very inter-related in their intent to provide support – and in our experience, the combined impact in residential aged care settings is rarely sufficient to meet the routine welfare and pastoral care needs of all residents.

ADACAS considers that routine welfare support should include:

- social support

[25] Australian Government Department of Health (2018) *Psychological Treatment Services for people with mental illness in Residential Aged Care Facilities.* Canberra: Australian Government Department of Health. Accessed via: https://www1.health.gov.au/internet/main/publishing.nsf/Content/PHN-Mental_Tools in July 2020.

- community development
- supporting people to connect with the communities outside of residential aged care
- time to listen to individuals as to where they are at/how they are/what they need, and to work with the person to support them in having their needs addressed in a way that works best for them.

Whether or not this type of support is available is likely to have a clear impact on mental health. There is a strong need to strengthen and diversify the welfare support that is available. Whilst ADACAS strongly supports the expansion of the Community Visitor Scheme (CVS), we also notes the natural limitations on the availability of volunteers to support and assist residents, and that it is imperative that schemes such as CVS are supplemented with the availability of more paid welfare support being made available in a targeted way, in the aged care facilities.

Time pressures on staff also impact on quality of care that people living in residential aged care receive and consequently the health and wellbeing of residents:

> *"the staff are rushed off their feet – some days I have to ask four different staff to get my pain tablets, before one of them remembers. The pain is really bad".*

Many people are entering aged care with complex health issues and/or disabilities: and for a large number, it is a place they are choosing (or finding themselves in) right at the end of life. Of those who died whilst living in residential aged care, the average lifespan after entering aged care is just under 3 years (32 months)[26].

The added impact of many deaths on the social and emotional wellbeing of people living in the aged care environment can be profound, especially given there are frequently extra barriers to developing or maintaining friendships, familial and community connections outside aged care facilities:

> *"I don't want to make any more friends here, they keep dying".*

It Is imperative that as a community we find more ways to ensure that people living in residential aged care be closely connected to the broader community and that the negative impacts on wellbeing that are currently occurring, are adequately responded to and addressed.

Pastoral care

When thinking of pastoral care, we are using the definition of palliAGED (an online evidence-based guidance and knowledge resource about palliative care in aged care, funded by the Australian government department of health): "Pastoral care is the care and support of the inner person. It is not necessarily about formal religion. Pastoral care respects and supports a person's particular belief systems and practices. It is holistic and person centred. The provision of pastoral care services in residential aged

[26] Australian Institute of Health and Welfare (2019), GEN fact sheet 2017-18: People leaving aged care. Canberra AIHW, accessed via: https://gen-agedcaredata.gov.au/Resources/Factsheets-and-infographics in July 2020

care (RAC) depends on the facility. Some services employ chaplains or pastoral care workers and some do not."[27]

Pastoral care can overlap with routine welfare support, but also might refer to spirituality, a definition of which can include: "Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions and practices".[28] For those who wish to access spiritual care, the National Guidelines for Spiritual Care in Aged Care emphasises: "As spirituality [can be] integral to quality of life and well-being, it should be accessible to all older people in way that is meaningful to their beliefs, culture and circumstances. . .". It is important to note the distinction between spiritual care and religious care as also explained in the National Guidelines on Spiritual care in Aged Care: "Spiritual care might be said to be the umbrella term of which religious care is a part. It is the intention of religious care to meet spiritual need. . . Spiritual care is not necessarily religious. Religious care should always be spiritual."[29]

Recommendation 14: That welfare and pastoral care support be additionally made systemically available at the level required in all residential aged care facilities to meet the needs of residents. That the design and approach to this support be co-designed with older people living at each residential aged care facility.

Recommendation 15: That access to and roles of the Community Visitor Scheme be expanded.

4.3.8. Impacts on wellbeing and mental health during COVID times

Throughout this COVID-19 pandemic, much effort has been invested by many across the aged care sector seek to balance the rights of people in residential aged care to have others visit them, with broader decisions to stop visitors to residential aged care to seek to reduce chances of a COVID-19 outbreak. Early in the pandemic, many aged care facilities opted to go into "lockdown" and to restrict the entry of visitors/travel out in the community by residents. In many cases, individual facilities were restricting visitor entry beyond the industry code[30] developed by COTA and supported by the Australian government.

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[27] Palliaged: *Palliative Care webpage*, accessed via https://www.palliaged.com.au/tabid/5571/Default.aspx in July 2020.

[28] Puchalski, C., Vitillo, R., Hull, S., & Reller, R. (2014). Improving the Spiritual Dimension of Whole Person Care: Reaching National and International Consensus. Journal of Palliative Medicine, 17(6), 642-656

[29] Meaningful Ageing Australia, (2016). *National Guidelines for Spiritual Care in Aged Care*. Meaningful Ageing Australia, Parkville. Accessed via: https://meaningfulageing.org.au/wp-content/uploads/2016/08/National-Guidelines-for-Spiritual-Care-in-Aged-Care-DIGITAL.pdf in July 2020.

[30] COTA (2020) *Industry code for visiting residential aged care homes during Covid-19*, accessed via https://www.health.gov.au/resources/publications/industry-code-for-visiting-residential-aged-care-homes-during-covid-19 in late July 2020.

Whilst pandemics are not common - "lockdowns" of residential aged care settings are not new. In Canberra in recent years, there have been multiple instances where various facilities have imposed a "lockdown" of some type (sometimes for a few days, at other times for a week or more)– usually due to outbreaks of gastroenteritis. Whilst appreciating the efforts to seek to minimise exposure to the health risks (and risks to life) that can come from conditions like gastroenteritis, and COVID-19, lockdowns and restriction of visitors can have a profound impact on the wellbeing and mental health of older people living in residential aged care – especially in situations where much of the limited welfare and wellbeing support that exists is entering externally (i.e. informal supports from family and friends of older people (for those sufficiently fortunate to have family or friends who are also in a position to visit regularly), or from community agencies, or other volunteer or supports (such as the Community Visitor Scheme, or external services). During a lockdown arrangement, if these visits cease (as they often are asked to do), and if opportunities for older people to go out into the community are also reduced, the impacts on the mental health and wellbeing of older people living in residential aged care can be profound – and are frequently not well planned nor catered for.

Whilst there will be some older people living in residential aged care who may be able to remain in contact with family or friends or others by phone, or video-chat – there will be others who do not have access to digital devices (tablets, computers etc), or who need support to be able to make phone-calls or access video-chat etc (support which due to staffing levels, is frequently unavailable).

ADACAS and other advocacy agencies have advocated for family members who are terrified that their loved one (an older person with dementia living in residential aged care) will forget them if they are not visiting them every day. Others notice the impact on the mood and wellbeing of their loved one becoming darker and darker. During the COVID pandemic, ADACAS is aware that many older people living in residential aged care are very isolated (and that they and their families) are very fearful of what will happen if there is an outbreak in their facility. Interstate, there have been reports of families who want to take their family member out of residential aged care, not being permitted to do so.

Isolation and seclusion are forms of restrictive practice (and also are sometimes used in prisons as a form of punishment for wrongdoing). In prisons though – isolation/seclusion is monitored, and time-limited and rights upheld in that way.

An older person in residential aged care during COVID spoke, filled with sadness and despair: "*now I know what prisoners feel like. Its extreme isolation. My family and friends can't visit. I can't see anyone, I can't go anywhere – the people around me have dementia, the staff are so busy that they don't have time to sit and listen to me. The TV news is all about deaths in aged care. It's frightening and so awful."*

The National Pandemic Mental Health and Wellbeing Plan emphasises the need to seek to reach people in community, ensuring that there are "services accessible in homes, workplaces, **aged care**, schools and other community sites"[31] (emphasis

[31] Australian Government National Mental Health Commission (2020), *National Pandemic Mental Health and Wellbeing Plan infographic*, available online at https://www.mentalhealthcommission.gov.au/getmedia/0ed417d3-

added). And advises “The importance of homes, aged-care facilities, schools, and workplaces as sites of mental health care has rapidly increased, particularly for individuals with existing, severe or complex mental health challenges”[32]. Despite this – in our view, it is clear despite everybody’s efforts that there has not been adequate provision and funding for ensuring that both the physical health care and mental health and wellbeing of older people living in residential aged care during the pandemic are being adequately addressed in a timely way. The impact on mental health and wellbeing was predictable, however does not seem to have been adequately funded or planned for. This is unacceptable, a breach of human rights, and the impacts on mental health and wellbeing are profound.

An older person living in residential aged care: *“I’m a lucky one – I can walk to a little garden near my room. But others are not so lucky. Most of the others here have been inside for the whole lockdown. They need to be able to get outside, sit in the garden and have a sunbath. The staff are so busy, that they don’t think to help people spend time outside in the gardens. Some people have been inside for almost five months. It's such a small thing, but it makes such a big difference”*

Recommendation 16: That there are urgent provisions made for appropriate levels of physical and mental health support and to safeguard the health and wellbeing of people living in residential aged care during the COVID-19 pandemic (and with any future infectious outbreaks).

Recommendation 17: That connections to families, friends and community are prioritised, and visits permitted in person to the extent that it is safely possible, and when not safe in person, that support and digital devices be made available such that people can connect via phone or video-chat.

Recommendation 18: That there are phone and digital solutions (tablets, computers, phones) urgently made available to support people being able to continue some contact with family and friends in situations where in person visits are not as possible, (and staff made available to support people to be able to use them as needed).

68c6-406f-8007-3975d01f7b59/National-Mental-Health-and-Wellbeing-Pandemic-Response-Plan-Infographic, accessed July 2020.

[32] Australian Government National Mental Health Commission (2020), *National Pandemic Mental Health and Wellbeing Plan*, available online via: https://www.mentalhealthcommission.gov.au/mental-health-and-wellbeing-pandemic-response-plan accessed July 2020.

5. Supported decision-making

ADACAS starts from the assumption that all people have capacity to make decisions[33]. However, we contend, that the opposite assumption about older people holds for many people in the community and generally in the delivery of aged care. This negative assumption is the result of the stereotyping and discrimination that is associated with the phenomenon known as "ageism"[34], whose constituent parts, prejudicial beliefs, discriminatory practices and institutional practices and policies[35] serve to perpetuate denial of choice and opportunity to older people. This can lead directly and indirectly to exclusion, negative experiences and/or various forms of abuse against older people[36]. The impact of ageism is an internalisation by the older person of individual lack of self-worth, less involvement and engagement in society, and an increased risk of abuse[37].

Questions about agency and an individual's capacity to make decisions and the concomitant requirement to appoint appropriate people within the community to take decisions on their behalf, have been central to the provision of service responses to vulnerable people for centuries, leading directly to the development of guardianship legislation in Australia and around the world[38]. Older people are often assumed to be vulnerable solely due to age, even before there is consideration of individual circumstances and whether there are factors which might contribute to increased vulnerability.

People with disability achieved a major landmark in 2006 with the acknowledgement and protection of their human rights in the United Nations Convention on the Rights of Persons with Disabilities (CRPD)[39] in which Article 12 "*Equal recognition before the law"*, includes the clause that *States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life*[40] The CRPD does not afford additional rights to people with disability, but rather affirms

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[33] Gear, Craig 2019, Transcript of Proceedings, In the Matter of the Royal Commission into Aged Care Quality and Safety, 12 February 2019, Auscript Australasia Pty Ltd, available [online] www.auscript.com.au

[34] The Benevolent Society 2017, *The Drivers of Ageism: Foundational research to inform a national advocacy campaign tackling ageism and its impacts in Australia*, available [online], https://d3n8a8pro7vhmx.cloudfront.net/benevolent/pages/393/attachments/original/1538977350/Ageism_Full_Report_Final.pdf?1538977350

[35] Ibid, p.15

[36] Australian Human Rights Commission (2013), *Fact or fiction? Stereotypes of older Australians Research Report, available [online] at* https://www.humanrights.gov.au/our-work/age-discrimination/publications/fact-or-fiction-stereotypes-older-australians-research, accessed August 2019, page 13.

[37] Council of Attorneys-General 2019, *National Plan to Respond to the Abuse of Older Australians [Elder Abuse] 2019-2023*, available [online]: www.ag.gov.au/ElderAbuseNationalPlan

[38] Australian Law Reform Commission (2014), 'Equality, Capacity and Disability in Commonwealth Laws (DP 81), 2. Conceptual Landscape—the Context for Reform Supported and substituted decision-making accessed from https://www.alrc.gov.au/publications/2-conceptual-landscape—-context-reform/supported-and-substituted-decision-making on 26/8/19.

[39] United Nations 2016, *Convention on the Rights of Persons with Disabilities (CRPD)*, available [online] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

[40] Ibid, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html

existing human rights to which everyone is entitled (regardless of age or disability). The CRPD informs the direction of Australia's policies regarding people with disability, including the development of the National Disability Strategy[41]. Whilst an equivalent convention affirming the rights of older people continues to be in development, the rights enshrined within the CRPD must be respected and applied to older people and indeed across the population as a whole. In Australia, as much as the focus on people with disability is now upon the primacy of their agency in determining positive outcomes, the same cannot be said about our approach to our older population and those in aged care.

5.1. Financial Abuse

Financial abuse of older people by their family members forms a significant number of the matters that ADACAS deals with in its advocacy. This often involves some form of control or coercion of finances and/or assets by the younger family member over the older person. In some cases, this can be a prelude to, or in parallel with, physical and other forms of abuse. It is not currently controversial that so many older people confer Enduring Power of Attorney (EPOA) to their adult children, in the event that they become unable to make important financial decisions (such as realising the value on their homes to afford the fee to enter a residential aged care facility (RACF). The Law Society of ACT strongly recommends that "everyone should have an Enduring Power of Attorney" [42]. Whilst the EPOA can be a safeguard if the appointed person fulfils their duties in upholding the rights of the older person, it can also, if misused, have the effect of denying the right to make decisions and choices by older people, and at other times be used as an instrument to facilitate financial abuse.

Mohammed (not his real name) contacted our office, explaining that he has started to have an uneasy feeling about what is happening with his finances. We assisted him to contact his bank – he discovered that a large sum of money ($10,000) had been removed (in smaller increments, over a three-month period of time) without his consent. When Mohammed asked his bank about this, they advised that they had acted on the instructions of his brother, (he had appointed his brother as his EPOA for financial matters shortly before moving into the aged care facility). Mohammad retains his full cognitive abilities, however had not usually been doing the finances (his wife had previously taken on that role, but had died shortly before he moved into care). Mohammad was devastated by these circumstances, and by his brother's actions. With help from a lawyer, he wrote to the bank, closed his accounts, and opened new ones with a different bank, with strict instructions that to accept only direct correspondence from Mohammad himself. He challenged his first bank's decision to accept the EPOA (without evidence that he had lost capacity). He also confronted his brother, who admitted to a gambling problem that had escalated. Whilst Mohammad had cancelled his brother's access to his accounts, even after he had cancelled his brother's appointment as his EPOA, his brother sought to use the paperwork to access

[41] Department of Social Services (DSS) 2010, *National Disability Strategy 2010-2020*, available [online]: https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020

[42] Law Society of ACT: https://www.actlawsociety.asn.au/public-information/making-an-enduring-power-of-attorney

Mohammad's funds at the new bank that Mohammad had chosen. It was some time afterwards that Mohammad also discovered that a credit card had been opened by his brother in his name (and debt accrued).

Advocacy is often provided to assist an older person who has been admitted to aged care against their will, and in many cases this also requires work to stall the sale of property, so that they have a home to return to.

5.2. Institutional Practices and Policies

The denial of choice and agency to residents of RACFs, which occurs frequently and is most often attributed to lack of staff, poor staff attitude and a lack of training, is a systematic expression of direct and indirect discrimination of older people. Aged care providers and staff representative bodies blame inadequate funding and/or management decisions for the abuse and neglect reported in RACFs such as the use of illegal restraints, both chemical and physical[43]. The law demands that a client consent to restraint and this is most often given by a substitute decision-maker. This situation provides little incentive for questioning the current practice of assessing people as lacking capacity and seeking instead to facilitate support decision-making. If illegal restraints are being deployed to cope with the lack of staffing, then there appears little scope for introducing more robust processes of seeking decisions that genuinely assert the will and preference of the resident. This points to a need to focus on supported decision-making (SDM) to facilitate choice as a requirement within the application of the Aged Care Standards.

ADACAS and researched and applied SDM as a tool to not only provide a viable alternative to formal substitute decision-making, but to improve the quality and quantity of decisions made by people with disability and older people[44]. In 2019 a literature review on the application of SDM as an intervention to the abuse of older persons found that while there has been very little research conducted on SDM directly, there are learnings from its application to other population groups that suggest it would be effective in all of the areas here identified as problematic for older people[45]. Of the relevant studies identified, half addressed the financial abuse of older people, with most effective strategies found to be building the individual's capacity for managing money, the provision of information, and the availability of trusted people to assist.

The distinction between legal capacity (the capacity to exercise autonomous decision making in the instruction of a legal representative or on a legal matter) and decision making ability can have especial impact on older persons. The place of supported decision making (where an individual uses supports to maximise active participation in a decision about their own lives) can mean the difference between respect for the lifetime of decisions, the values will and preference of an older person being offered

[43] The Canberra Times, 21 August 2019, New Rules on physical restraint in aged care could backfire, inquiry told: https://www.canberratimes.com.au/story/6337551/new-rules-on-physical-restraint-in-aged-care-could-backfire-inquiry-told/

[44] See for example: http://www.adacas.org.au/supported-decision-making/supported-decision-making-training/

[45] Strickland, K., Bail, K., Cope, S. and Turner, M. 2019, *Final Report: Supported Decision-Making and Individual Advocacy as Tools to assist older persons experiencing elder abuse*, University of Canberra, conducted for ADACAS and OPAN.

the respect we would all seek and a substitute decision being imposed which includes the risk of those rights being denied. It is a commonly reported event that, regardless of the parameters of an order or the powers offered to an attorney, systems and services will seek and consult the substitute decision maker as a convenience to avoid communication support needs, because it takes less time or because interests are aligned with theirs rather than those of an individual.

Kuna experienced a recent onset of memory impairment and sought support to attend an appointment with legal advisors to prepare a will. Using a supported decision making model Kuna identified the decisions to be made and the supports needed to map, reflect and record the decisions required to prepare a will. He went through dispensations and details with the legal advisor in great detail referring to notes made and occasionally checking strategies for remembering with supports present. The legal advisor was confident all questions had been answered to enable preparation of the will but finished with a need to seek a written medical opinion that Kuna had capacity with reference to his stated memory impairment. The support of advocacy allowed for clarification that memory impairment does not equate with decision making impairment and that the clear reasoning and declaration of decisions on this matter were made in line with the lived experience of Kuna's values, will and preferences and evidenced by past decisions. The alternative proposed was the appointment of a guardian, a source of great distress to Kuna who could not identify someone in his life to take this role and felt it was unacceptable that a stranger should make determinations he felt able to make himself.

Recommendation 19: The Royal Commission needs to look at how facilities should run in order to facilitate best practice in SDM, and not rush to judgements on staffing and funding levels without taking into account the need for staff to have adequate time to support decisions when this assistance is wanted or needed (acknowledging that it is a right if people have a disability, for people to have access to this support).

6. Conclusion

ADACAS is a member of the Older Persons Advocacy Network (OPAN), which has shown itself to be a trusted agent for older people during this COVID-19 crisis. Advocacy for older people in aged care has now been recognised as having true value within a complex system, and a strong voice for the consumer in the push for reform toward a better and more equitable system for all older Australians.