

# Response to Royal Commission into Aged Care Quality and Safety – Capacity Guardianship and Supported Decision Making

August 2019

Contact:

Michael Bleasdale

CFO

manager@adacas.org.au

0447 423 185

© 2019 ADACAS - ACT Disability Aged & Carer Advocacy Service Inc - ABN 15 750 251 576

Unit 14 – 6 Gritten Street, Weston Community Hub, Weston Creek ACT 26111

PO Box 6137, Weston Creek ACT 2611

P: 61 02 6242 5060 | F: 61 02 6242 5063 | E: adacas@adacas.org.au | W: www.adacas.org.au

This page is intentionally blank

# **Table of Contents**

1.	About ADACAS and OPAN	4
2.	Scope of the Submission	4
3.	Issues of concern	5
3.1. Capacity	,	5
3.2. Guardianship		10
3.3. Supported Decision Making		11
4.	A way forward	13
5.	Recommendations	14

# 1. About ADACAS and OPAN

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 28 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. ADACAS is funded by the Australian and ACT Governments to provide this advocacy support. In addition, we offer Support Coordination to a number of NDIS participants within the ACT, primarily people who have complex disability and/or health needs and whose life circumstances require specialised and expert management and linkage with customised services.

In addition, ADACAS has a respected research and projects capability which has for the past decade specialised in Supported Decision Making (SDM) and has received funding though ACT and Commonwealth grants. This work is recognised nationally and internationally.

ADACAS undertakes its advocacy work to older people in the ACT as one of the nine sub-contracted service delivery organisations (SDOs) that make up the Older Persons Advocacy Network (OPAN). OPAN's free services support older people and their representatives to address issues related to Commonwealth funded aged care services. OPAN is funded by the Australian Government to deliver the National Aged Care Advocacy Program (NACAP). OPAN provides a national voice for aged care advocacy and strives to promote excellence and national consistency in the delivery of advocacy services under the NACAP.

OPAN is always on the side of consumers. It is an independent body with no membership beyond the nine SDOs. This independence is a key strength both for individual advocacy and for our systemic advocacy.

# 2. Scope of the Submission

This brief submission looks at issues of capacity as they relate to older people who, as they age, are frequently subjected to questions about their ongoing ability to make decisions and exercise choice over their own affairs. The submission will limit itself to the:

- concerns of older people about how their choices are denied, in many case by family, and often in an aged care or community setting,
- formal mechanisms that are in place to make substitute decisions for older people and how these can be abused, and
- increased focus upon supported decision making, as a viable alternative to assist older people to continue making decisions as they age.

The submission is informed in equal part by the advocacy that ADACAS delivers to older people in the ACT, and by the research and project work we have conducted and directed to the issue of capacity, substitute decision making (guardianship) and supported decision making over the past decade. Wherever possible the submission

aims to point out issues and solutions that have been identified through investigation and research, and which are illustrated by the instances of advocacy provided in our daily work.

# 3. Issues of concern

## 3.1. Capacity

#### Introduction

The position of ADACAS and our partners at OPAN is that we start from an assumption that people have capacity to make decisions.¹ It is our contention 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 a particular representation of the stereotyping and discrimination that is associated with the phenomenon known as "ageism"², whose constituent parts, prejudicial beliefs, discriminatory practices and institutional practices and policies³ 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.⁴ The impact of ageism is an internalisation of individual lack of self-worth, less involvement and engagement in society, and an increased risk of abuse.⁵

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. <sup>6</sup> 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

<sup>&</sup>lt;sup>1</sup> 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

<sup>&</sup>lt;sup>2</sup> 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], <a href="https://d3n8a8pro7vhmx.cloudfront.net/benevolent/pages/393/attachments/original/1538977350/Ageism\_Full\_Report\_Final.pdf">https://d3n8a8pro7vhmx.cloudfront.net/benevolent/pages/393/attachments/original/1538977350/Ageism\_Full\_Report\_Final.pdf</a>? 1538977350

<sup>&</sup>lt;sup>3</sup> Ibid, p.15

<sup>&</sup>lt;sup>4</sup> Australian Human Rights Commission (2013), Fact or fiction? Stereotypes of older Australians Research Report, available [online] at <a href="https://www.humanrights.gov.au/our-work/age-discrimination/publications/fact-or-fiction-stereotypes-older-australians-research">https://www.humanrights.gov.au/our-work/age-discrimination/publications/fact-or-fiction-stereotypes-older-australians-research</a>, accessed August 2019, page 13.

<sup>&</sup>lt;sup>5</sup> 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

<sup>&</sup>lt;sup>6</sup> 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 <a href="https://www.alrc.gov.au/publications/2-conceptual-landscape—context-reform/supported-and-substituted-decision-making">https://www.alrc.gov.au/publications/2-conceptual-landscape—context-reform/supported-and-substituted-decision-making</a> on 26/8/19.

of Persons with Disabilities (CRPD)<sup>7</sup> 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.<sup>8</sup> The CRPD does not afford additional rights to people with disability, but rather affirms 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.<sup>9</sup> 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.

## Prejudicial Attitudes

Assumptions about the capacity of people who are identified as having disability have, due to the focus of the CRPD, been challenged from that of an inability and thus a denial of right to make decisions, to one of a requirement by society to address the function of making decisions and supporting that function for these individuals. This same focus has not been applied to older people in general, and not just specifically to people with dementia. It is widely assumed that the decline in functions that can attend ageing, particularly at the latter stages of life, will necessarily lead to a decline in the ability to make or participate in decisions. This assumption fails to acknowledge the process by which individuals, including older people, will involve trusted others to assist and support them in reaching decisions that affect their lives, as well as the lifelong experience they have had in making decisions.

Research has been focused in recent years upon the growing prevalence of dementia amongst our ageing population. It concludes that attitudes toward this condition need to change, both in the community and in aged care, in order for us to sustain and maintain in wellness, people with dementia in a range of accommodation settings. The work of the Cognitive Decline Partnership Centre<sup>10</sup> considered the issues of rights and principles particularly in relation to persons with dementia. Challenges to the prevalence of substitute decision-making for people with dementia, and to the absence of choice-making options, are based not only on the affirmation of the right to self-determination but on the importance that retaining this function has to a person's sense of self, which is integral to their overall wellbeing.<sup>11</sup>

<sup>&</sup>lt;sup>7</sup> 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

<sup>&</sup>lt;sup>8</sup> Ibid, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html

<sup>&</sup>lt;sup>9</sup> Department of Social Services (DSS) 2010, *National Disability Strategy 2010-2020*, available [online]: <a href="https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020">https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020</a>

<sup>&</sup>lt;sup>10</sup> Sinclair, C., Field, **S.**, Blake, M. (2018). Supported decision-making in aged care: A policy development guideline for aged care providers in Australia. Sydney: HammondCare

#### 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" 12, but if this is to act as a genuine safeguard, additional controls need to be in place to guide and monitor the behaviour of those who operate EPOAs. One of the short to medium term strategies of the National Plan to respond to the Abuse of Older Australians [Elder Abuse] is to "investigate the feasibility of developing a national online register of enduring powers of attorney". 13 Our advocacy to older people who report abuse is significantly related to financial abuse, which is often perpetrated by the family member(s) who has the EPOA.

Whilst the appointment of an Enduring Power of Attorney (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.

Tom has been living alone in his own home for many years since he was widowed. He manages personal care tasks and receives assistance from neighbours, friends and some paid supports to complete domestic and some community access tasks. He appointed his daughter EPOA some time ago and she is now living interstate with her partner. They visit after Tom has a fall and is admitted to hospital. They describe Tom's declining memory and suggest he no longer has capacity to make decisions that keep him safe including where he lives. The hospital recognises the concerns and arranges a respite stay in a residential aged care facility for Tom to allow time for improvement in his mobility. During this stay his daughter and son-in-law leave but change the locks on the property to deny access to friends and neighbours who have had keys to offer support to Tom. They commence proceedings for sale of the house using their EPOA.

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.

<sup>&</sup>lt;sup>11</sup> Cognitive Decline Partnership Centre 2018, *Supported Decision-Making in Aged Care: A Policy Development Guidelines for Aged Care Providers in Australia*, <a href="https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/SDM-Policy-Guidelines.pdf">https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/SDM-Policy-Guidelines.pdf</a>

<sup>&</sup>lt;sup>12</sup> Law Society of ACT: https://www.actlawsociety.asn.au/public-information/making-an-enduring-power-of-attorney

<sup>&</sup>lt;sup>13</sup> Council of Attorneys-General 2019, *National Plan to Respond to the Abuse of Older Australians [Elder Abuse]* 2019-2023, available [online]: <a href="www.ag.gov.au/ElderAbuseNationalPlan">www.ag.gov.au/ElderAbuseNationalPlan</a>

#### **Discriminatory Practices**

Age related discrimination (when someone is treated less favourably due to their age<sup>14</sup>), can be a common experience of older people, in workplace settings (both recruitment and in the workplace), in retail settings and also in healthcare.<sup>15</sup> Whilst such discrimination is illegal, it can be challenging for individuals to prove that discrimination has occurred, and to counter it.<sup>16</sup> Older people report that workplace discrimination is a significant barrier to employment.<sup>17</sup> It is incumbent on government and the community to partner and provide leadership around challenging ageism, such that discrimination is being identified, challenged and changed at all levels: systemic, organisational and individual.<sup>18</sup>

Ageism and discriminatory attitudes can also be found in patronising and/or offensive and/or infantilising language: "the oldies", "honey", "pet", "old dear", "grumpy old man" etc or through language choices in policy/political concepts which characterise the level of funding needed by older Australians as creating a "burden". 19 Whilst such language is sometimes discounted as trivial, or dismissed as having been said as part of a joke, the attitudes highlighted in such statements expose underlying beliefs and attitudes which are having a pervasive impact in other settings. 20 Capacity, or its diminution, is present in all of the stereotypes which result in discrimination against older people.

Discriminatory practices, based on assumptions of (in)capacity, are prevalent in many community institutions, including financial institutions where there is increasing pressure to safeguard the funds of vulnerable clients, which at times results in judgements being made about the capacity of these clients to make decisions about their finances. This is beginning to be addressed by some through training and the

<sup>&</sup>lt;sup>14</sup> Australian Human Rights Commission website (2019) *Age Discrimination* accessed online via: https://www.humanrights.gov.au/our-work/employers/age-discrimination in August 2019

<sup>&</sup>lt;sup>15</sup> Australian Human Rights Commission, *Australian Human Rights Commission 2017-2018 Complaint Statistics*, accessed online via: <a href="https://www.humanrights.gov.au/sites/default/files/AHRC\_Complaints\_AR\_Stats\_Tables\_2017-18.pdf">https://www.humanrights.gov.au/sites/default/files/AHRC\_Complaints\_AR\_Stats\_Tables\_2017-18.pdf</a> in August 2019.

<sup>&</sup>lt;sup>16</sup> Australian Human Rights Commission (2016) *Willing to Work: National Inquiry into Employment Discrimination Against Older Australians and Australians with a Disability*, accessed online via: <a href="https://www.humanrights.gov.au/our-work/disability-rights/publications/willing-work-national-inquiry-employment-discrimination">https://www.humanrights.gov.au/our-work/disability-rights/publications/willing-work-national-inquiry-employment-discrimination in August 2019, page 35.

<sup>&</sup>lt;sup>17</sup> Australian Human Rights Commission (2016) *Willing to Work: National Inquiry into Employment Discrimination Against Older Australians and Australians with a Disability*, accessed online via: <a href="https://www.humanrights.gov.au/our-work/disability-rights/publications/willing-work-national-inquiry-employment-discrimination in August 2019">https://www.humanrights.gov.au/our-work/disability-rights/publications/willing-work-national-inquiry-employment-discrimination in August 2019</a>.

<sup>&</sup>lt;sup>18</sup> Australian Human Rights Commission (2012): Working past our 60s: Reforming Laws and Policies for the Older Worker, accessed online via: <a href="https://www.humanrights.gov.au/sites/default/files/content/age/publications/Working\_past\_our\_60s\_2012.pdf">https://www.humanrights.gov.au/sites/default/files/content/age/publications/Working\_past\_our\_60s\_2012.pdf</a> in August 2019.

<sup>&</sup>lt;sup>19</sup> The Benevolent Society (2017), *The drivers of ageism report*, accessed online via: <a href="https://d3n8a8pro7vhmx.cloudfront.net/benevolent/pages/393/attachments/original/1538977350/Ageism\_Full\_Report\_Final.pdf?1538977350">https://d3n8a8pro7vhmx.cloudfront.net/benevolent/pages/393/attachments/original/1538977350/Ageism\_Full\_Report\_Final.pdf?1538977350</a> in August 2019, page 43.

The Benevolent Society (2017), The drivers of ageism report, accessed online via: <a href="https://d3n8a8pro7vhmx.cloudfront.net/benevolent/pages/393/attachments/original/1538977350/Ageism\_Full\_Report\_Final.pdf?1538977350">https://d3n8a8pro7vhmx.cloudfront.net/benevolent/pages/393/attachments/original/1538977350/Ageism\_Full\_Report\_Final.pdf?1538977350</a> in August 2019, page 42.

design of facilities which actively encourage older people to transact at local branches.<sup>21</sup>

#### Institutional Practices and Policies

The institutionalisation of discriminatory practices in relation to capacity is evident in the practices of assessment of capacity, which occur to some extent within financial institutions but is very common in the healthcare system. Capacity assessments are routinely performed when assessing people for eligibility for a range of government-funded programs, and in healthcare settings, when determining what medical and/or rehabilitation procedures may be required. A person's capacity to make decisions is commonly questioned when there are treatment options to be made and the person is acutely unwell. In addition to treatment, the issue of capacity comes up when considering discharge from hospital and can lead to premature placement in RACFs without adequately exploring other alternatives to assist people to remain at home.

The denial of choice and agency to residents within RACFs, which occurs frequently and is most often attributed to lack of staff, poor staff attitude and a lack of training, is a systemic 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.<sup>22</sup> 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 supported 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 this as a requirement within the application of new Aged Care Standards.

The Royal Commission should consider how facilities could facilitate best practice in SDM before finalising any recommendations on staffing and funding levels. These considerations must include 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).

The practice of most RACFs (in the ACT at least) to demand all residents have an Enduring Power of Attorney (EPOA) as a requirement of admission, whilst regarded as a sensible safeguard, can also be viewed as an expression of discrimination. It assumes that all will lack the capacity to determine their own wellbeing at some point in the future. The impact on some residents of having an EPOA is that family members, rather than residents themselves, are consulted on matters that are intensely personal, including placing restrictions on personal contact and relationships which are clearly in breach of individual human rights. And there is little

Royal Commission Aged Care - ADACAS 1st Submission for OPAN- FINAL

<sup>&</sup>lt;sup>21</sup> See for example Beyond Bank <a href="https://www.beyondbank.com.au/your-community/support/aged-care/dementia-australia.html">https://www.beyondbank.com.au/your-community/support/aged-care/dementia-australia.html</a>

<sup>&</sup>lt;sup>22</sup> The Canberra Times, 21 August 2019, New rules on physical restraint in aged care could backfire, inquiry told, <a href="https://www.canberratimes.com.au/story/6337551/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/</a>

incentive for RACFs to facilitate more involved supported decision-making processes.

## 3.2. Guardianship

The previous section introduced the practice of guardianship as a means to support people who have been deemed to lack capacity to make decisions that affect their lives. This section will briefly address where guardianship, applied as a formal, legal mechanism, can impact negatively upon older people.

Review of Guardianship legislation in Australia continues around the country but is different in each State and Territory, both in the way it can apply to individuals and in the state-run bodies which set and administer orders.<sup>23</sup> Of primary significance is the manner in which a guardian must act, determining that any decisions made on behalf of another, as far as possible, reflect the values, will and preference of the person, unless such wishes are likely to have significant adverse effect. It is the experience of ADACAS that this guidance is often neglected in favour of a "best interests" substitute decisions, where the guardian acts in a way aligned more closely with their own wishes.

It is important to state that ADACAS and OPAN accept that in some circumstances, guardianship does provide a real safeguard for people who are vulnerable and can be beneficial when applied properly. The advocacy we provide, however, has identified instances where it has been misapplied (often by private guardians, often family) resulting in a denial of an older person's human rights.

Sach had a long standing guardianship order under which a family member was responsible for decisions about health and accommodation. After an occasion where Sach became unwell, a regimen of medication management was instituted by the service providers to which the guardian consented. This regimen became increasingly intrusive for Sach including checking cupboards and refrigerator for food quality and limiting access to other activities to be available for scheduled medication visits. Sach became increasingly frustrated and attempted to communicate a wish for change to the service providers without success. Eventually, Sach sought advocacy support to alter the situation. She demonstrated increasing independence in administering her own medication, attended a course to gain a better understanding of her condition and its impact on her health and had no further episodes of serious ill health related to that condition. A proposal was made to gradually reduce the supervisory visits and a discussion facilitated by advocates with service providers and quardian to institute a change in line with Sach's preference. Concerns were expressed in response to risk, as demonstrated on the initiating occasion. The service providers maintained that the existing procedure was the only way to deliver support. The guardian consented and the process remained in place. Sach felt no consideration had been made of her preference, the value she placed on independently setting her daily timetable or the efforts she had made to demonstrate

\_

<sup>&</sup>lt;sup>23</sup> Australian Law Reform Commission (2014), 'Equality, Capacity and Disability in Commonwealth Laws (DP 81), 10. Review of State and Territory Legislation Guardianship and administration accessed from https://www.alrc.gov.au/publications/2-conceptual-landscape—context-reform/supported-and-substituted-decision-making on 26/8/19.

her willingness to maintain a regular and supervised procedure without the intrusive support she had been receiving. The guardian acted in what he believed was the best interests of Sach. Sach did not want to fracture the important and supportive relationship with family but remained very frustrated and distressed. The only recourse to change was to make an application for review of the order, a process which was daunting and anxiety provoking to Sach and, in her view, carried risk that other supports would thereby be removed by family or providers. The discriminatory assumptions exercised in an ongoing way and based on a single historical event would be seen as unacceptable if applied to anyone who had not had their capacity questioned.

Overall, guardianship and financial management by a substitute decision-maker must now, since the application of the CRPD, been seen very much as a last resort, and alternatives to these arrangements must be sought to a greater degree than has been the practice in the past.

### 3.3. Supported Decision Making

This submission is critical of the lack of respect for choices of older people which is endemic across our community and its institutions. This section will identify some practices which are actively challenging current practices, in particular the application of Supported Decision Making (SDM). SDM is:

"a central principle of the United Nations Convention on the Rights of Persons with Disabilities. People with disability should receive the support necessary to enable them to make and implement the decisions that affect them." <sup>24</sup>

ADACAS has 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. <sup>25</sup> In 2019, a literature review on the application of SDM as an intervention to abuse of older persons found that while there has been very little research conducted on SDM directly in this area, 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. <sup>26</sup> Of the relevant studies identified, half addressed the financial abuse of older people, with the most effective strategies found to be building the individuals' capacity for managing money, the provision of information, and the availability of trusted people to assist. There was also evidence that the banking industry is amenable to directly addressing the issue of assumptions about the capacity of people with dementia through the development of online education tools for staff. <sup>27</sup>

\_\_\_

<sup>&</sup>lt;sup>24</sup> Victorian Office of the Public Advocate, available [online]: <a href="https://www.publicadvocate.vic.gov.au/advocacy-research/supported-decision-making">https://www.publicadvocate.vic.gov.au/advocacy-research/supported-decision-making</a>

<sup>&</sup>lt;sup>25</sup> See for example http://www.adacas.org.au/supported-decision-making/supported-decision-making-training/

<sup>&</sup>lt;sup>26</sup> Strickland, K., Bail, K., Cope, S. and Turner, M. 2019 (forthcoming), *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.

<sup>27</sup> ibid

The benefits of supported decision making summarised by Piers Gooding in 2015 "include: the promotion of personal autonomy, authority and control for people over their own lives; the use of a more realistic account of autonomy and decision making which take into account a person's social context and interdependence; providing a clear structure for addressing decision making by people who may require support to make decisions, or whose will and preference is unclear;" <sup>28</sup>

All these have potential benefits for older persons and for our community in influencing the manner and process of delivering support to uphold equally the rights of all people. 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. Supported decision-making can mean the difference between offering the older person the respect we would all seek (respect for a lifetime of decisions, one's values, will and preferences) 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.

There is increasing evidence that supported decision making confers benefits upon older people, including those living in RACFs and people with dementia. Whilst supported decision making in the community is best provided by trusted family members and friends, the closed setting of the RACF demands alternative strategies, and the *Supported Decision-Making in Aged Care* guidelines<sup>29</sup> gives providers the

Royal Commission Aged Care - ADACAS 1st Submission for OPAN- FINAL

<sup>&</sup>lt;sup>28</sup> Gooding, P. 2015, Navigating the 'Flashing Amber Lights' of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns, *Human Rights Law Review*, Vol. 15, Issue 1, pp 45-71, pp 3-4.

<sup>&</sup>lt;sup>29</sup> Cognitive Decline Partnership Centre 2018, *Supported Decision-Making in Aged Care: A Policy Development Guidelines for Aged Care Providers in Australia*, <a href="https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/SDM-Policy-Guidelines.pdf">https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/SDM-Policy-Guidelines.pdf</a>

tools to achieve this, in the context of meeting the Aged Care Standards.

# 4. A way forward

The CRPD affirms the inalienable rights for persons with disability, a group that routinely had been denied those rights, some, for many centuries. This Convention underpinned legal and regulatory mechanisms in Australia and around the world that are positively addressing the denial of rights. A commitment to a similar convention for older people, based on the recognition that many older people are rendered vulnerable by lesser access to the rights expected by the rest of the community, would be a significant starting point for addressing the ageism that underpins the issues of capacity and denial of dignity of decision-making that this submission addresses. Such a convention would need to address the issue of equality before the law, and require its signatories to commit to policies, strategies and legal changes that addresses the endemic denial of rights to older people based on their capacity.

The need to monitor Enduring Powers of Attorney (EPOA) and to develop a consistent approach to this across Australia is already acknowledged.<sup>30</sup> This needs to be addressed urgently, together with a commitment to develop educative resources that can ensure all people who make substitute decisions on behalf of older persons do so in accordance with the principle of respecting the older person's will and preferences.

Wherever possible supported decision making (SDM) should be adopted to enable any older person, in any aged care setting, to access this support in order to actively make choices. This support would truly activate the principle of *consumer-directed care*<sup>37</sup> in the quality of supports delivered, as well as in the decision about which agency will provide those services. The tools available for this purpose already reference and track the Aged Care Standards, and in determining how the quality of support can be improved, the Royal Commission might also consider SDM as a requirement that drives staffing and the way that care, and support is delivered.

<sup>&</sup>lt;sup>30 30</sup> 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, p.10

<sup>31</sup> See:

https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/04 2015/what is consumer directed care 0 0.pdf

# 5. Recommendations

#### It is recommended that:

- Considerations on staffing or funding in relation to RACFs consider how facilities could implement best practice SDM with individuals who want or need this support.
- Compulsory training on implementing SDM be required in aged care.
- ACQSC quality audits include a requirement for aged care services to produce substantial evidence of implementing SDM.

14