OPAN Older Persons Advocacy Network

Supported decision-making must be embedded across aged care

Position Statement

November 2022

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Overview

Overall, OPAN supports the intention of the United Nations' Convention on the Rights of People with Disabilities in relation to supported decision-making and Article 12: Equal Recognition before the law (as explored in (1)). While OPAN agrees with the urgent need to cease the current use of substitute decision-makers in Australia to reduce the abuse of older people, we recognise that substitute decision-making may still be required in rare and exceptional cases where all possible options to support an older person to make their own decisions have been exhausted or are impossible (e.g. if the person is in a coma). The OPAN Position in this paper explores how to realise the right that older people, like all adults, have to make decisions about the care and services they receive and the risks they are willing to take and ensure this right is equally recognised under law. The second part of this paper explores key concepts that underpin the OPAN Position.

Sach's Story

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, their guardian consented to a regimen of medication management instituted by the service provider. This regimen became increasingly intrusive for Sach including checking cupboards and refrigerator for food quality and limiting access to other activities in order 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. They demonstrated increasing independence in administering their own medication, attended a course to gain a better understanding of their condition and its impact on their 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 guardian 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 their preference, the value they placed on independently setting their daily timetable or the efforts they had made to demonstrate their willingness to maintain a regular and supervised procedure without the intrusive support they 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 their 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.

Reproduced from OPAN submission on capacity, guardianship and supported decision-making to the Royal Commission into Aged Care Quality and Safety prepared by the ACT Disability Aged & Carer Advocacy Service Inc., 2020.

OPAN Position

Foundational statements regarding older people and decision-making

1. As with all adults; older people have the right to make decisions about the care and services they receive and the risks they are willing to take.
2. The presumption must always be that older people have the ability to make decisions.
3. A reduction in decision-making ability is not a result of ageing:
    a. Most people have the ability to make decisions about all aspects of their life until their death.
    b. Some adults of any age may want and/or need support in making certain types of decisions.
    c. Only in rare cases will adults require support in making all decisions.
4. Decision-making ability is complex, fluctuating and difficult to assess. Decision-making ability depends on many factors, including but not limited to:
    a. the quality of information provided and the suitability of the format it is provided in,

b. available supports to make a decision,
c. the person's confidence and/or knowledge relating to the decision topic,
d. the person's communication modes and preferred language,
e. cultural differences in expressions and values,
f. the type of decision made, and
g. fluctuating abilities with time.

5. The presumption of decision-making ability should only be diverged from when the complex nature of decision-making ability has been fully considered and all possible options to support a person to make their own decisions have been exhausted or are impossible (e.g. if the person is in a coma).

Enshrining the rights of older people to make decisions and realise their right to legal capacity in aged care

6. Supported decision-making should be the first and preferred option, with substitute decision-making seen as a last resort that would only need to be implemented in rare and exceptional cases.
7. A national policy and legislative framework for supported decision-making and substitute decision-making should be codesigned with people with a range of disabilities, cultural backgrounds, ages and diverse groups.
8. The codesigned national policy and legislative framework should be embedded in federal, state and territory laws, policies and legal frameworks across all care and support sectors (including aged care) and spanning all types of supporters (including family, friends, advocates, support workers and legally appointed supporters.)
9. The codesigned national policy and legislative framework should include provisions for effective guidelines and safeguards[1]. This framework should include:
   a) The eight National Supported Decision-Making Principles proposed by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Box 2).
   b) A focus of advance directives on outlining the wills and preferences of the individual to assist in decision-making. These advance directives may also specify supporters and substitute-decision makers and should specify the point(s) at which a person wants supported decision-making or substitute decision-making to be in force.
   c) A requirement that, in the rare cases they are legally appointed, substitute decision-makers must make decisions based on a best interpretation of will and preferences of an individual not 'in their best interests'.

[1] See OPAN's 2022 submission in response to the guidelines and safeguards proposed by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2).

d) A requirement that criteria used in assessments of decision-making abilities must be continually revised and improved through explorations of how they are implemented in real-life decisions.

10. In addition to embedding the national policy and legislative framework, aged care legislation and policies, plus aged care service policies, must explicitly state and address the foundational OPAN position statements regarding older people and decision-making.

National Supported Decision-Making Principles proposed by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Principle 1: Recognition of the equal right to make decisions

All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

Principle 2: Presumption of decision-making ability

All adults must be presumed to have ability to make decisions that affect their lives.

Principle 3: Respect for dignity and the right to dignity of risk

All adults must be treated with dignity and respect and supported to take risks to enable them to live their lives the way they choose, including in their social and intimate relationships.

Principle 4: Recognition of the role of all* supporters and advocates

The role of all* supporters and advocates who provide supported decision-making should be acknowledged and respected.

Principle 5: Access to support necessary to communicate and participate in decisions

Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

Principle 6: Decisions directed by a person's own will, preferences and rights

The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

Principle 7: Inclusion of appropriate and effective safeguards against violence, abuse, neglect or exploitation

Laws and legal frameworks must contain appropriate and effective safeguards for interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

Principle 8: Co-design, co-production and peer-lead design processes

People with a range of disabilities, cultural backgrounds and ages** and their representative organisations should be involved in the reform and development of laws, policies and legal frameworks.

*This is a modification to Principle 4 as suggested by OPAN, with 'all supporters' replacing 'informal supporters' to ensure the principles encompass legally appointed supporters and the full range of people who may provide support.

** This is a modification to Principle 4 as suggested by OPAN, with 'People with a range of disabilities, cultural backgrounds and ages' replacing 'People with disability'.

Reproduced from Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Roundtable. Supported decision-making and guardianship: proposals for reform [Internet]. Commonwealth of Australia; 2022 May [cited 2022 Sep 12]. Available from: https://disability.royalcommission.gov.au/publications/supported-decision-making-and-guardianship-proposals-reform-roundtable#:~:text=The%20Disability%20Royal%20Commission%20held,autonomy%20of%20people%20with%20disability.

Enforcing the rights of older people to make decisions in aged care

11. The national supported decision-making policy and legislative framework must include a specified body with the powers to enforce relevant charges and sanctions for individuals and entities (including aged care service providers) who do not uphold the supported decision-making principles.
12. All providers of aged care services, including screening and assessment services, must ensure access to supported decision-making by a supporter, independent of the service, to all individuals who want or need this support. [2]
13. Aged Care Quality and Safety Commission quality audits must include specified requirements[3] for aged care services to produce substantial evidence of:
    a. how their workers implement supported decision-making principles in day-to-day practice, and
    b. how they provide access to independent supporters.

Enabling supporters, services and older people to engage in supported decision-making

"In order to comply with the requirement, set out in article 12, paragraph 3, of the Convention, for States parties to take measures to "provide access" to the support required, States parties must ensure

[2] This could be implemented through an addition to Aged Care Quality Standard 1. Consumer Dignity and Choice. Requirement 3(c) (3).
[3] Noting these are currently just examples of acceptable evidence relating to Aged Care Quality Standard 1. Consumer Dignity and Choice. Requirement 3(c) (3).

that support is available at nominal or no cost to persons with disabilities and that lack of financial resources is not a barrier to accessing support in the exercise of legal capacity" (United Nations Committee on the Rights of Persons with Disabilities, 2014 (1), paragraph 29(e))

The Australian Government should:

14. Adequately fund professional advocates as potential supporters in aged care decision-making processes, should the older person choose to seek the support of an advocate.
15. Promote and ensure access to existing supported decision-making resources, further develop relevant resources, initiatives and partnerships (through co-design where possible), and support a Knowledge Hub to consolidate supported decision-making resources for everyone including aged care workers, families, health and allied health professionals, families, friends and other informal caregivers.
16. Launch a national public awareness campaign to promote understanding of what supported decision-making is and why it is relevant in preventing and/or minimising elder abuse and maximising the rights of older people to make decisions and take risks.
17. Embed supported decision-making principles and practices in all educational and training programs relating to those working with older people who want or need support to make decisions.
18. Compulsory training for all people providing aged care services must be provided on:
    a. supported decision-making principles and practices,
    b. ageism, unconscious bias and elder abuse,
    c. human rights, and breaches therefore, related to decision-making and risk-taking,
    d. the differences between communication ability and mode, cultural differences in expressions and values, psychosocial disabilities, memory loss, and abilities related to making specific decisions,
    e. decision-making ability versus legal capacity, and
    f. supported decision-making principles and practice.

This could be achieved through integration in the adoption of the following Royal Commission into Aged Care Quality and Safety recommendations:

- Recommendation 79: Review of certificate-based courses for aged care
- Recommendation 80: Dementia and palliative care training for workers
- Recommendation 81: Ongoing professional development of the aged care workforce.

- Recommendation 82: Review of health professions' undergraduate curricula

19. Consider the need for a funding model that makes provisions for aged care workers to allocate an adequate amount of time to supported decision-making.

Background to key concepts underlying OPAN positions

Elder abuse enabled by decision-making frameworks

OPAN's network of nine state and territory aged care advocacy organisations have first-hand experience of how substitute decision-making currently leads to the abuse older people by family members, friends, health and aged care service providers (which are a type of institution, whether support is provided in the community or home) (see, for example (4)). Data from the Queensland Elder Abuse Protection Unit 2020-21 financial year data analysis found that:

> *"In 80.2 percent of cases (n = 404) in which a formal decision-making arrangement was in place and perpetrator status was known, one or more decision makers were recorded as perpetrators [of the elder abuse]."* (Elder Abuse Protection Unit, 2021 (5), p.29)

Core to this issue is the ageism that is ubiquitous in our society and internalised by many older people themselves. This means older people are in a perceived, and actual, power imbalance with younger family members, service providers and others as they feel and are treated as 'less than' in a multitude of ways (see compass.info webpage on Ageism and references therein for more information (6)). This power imbalance due to ageism is further exacerbated by people abusing their positions of power, for example as a substitute decision-maker, to exert undue influence.

> *"All people risk being subject to "undue influence", yet this may be exacerbated for those who rely on the support of others to make decisions. Undue influence is characterized as occurring, where the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation. Safeguards for the exercise of legal capacity must include protection against undue influence; however, the protection must respect the rights, will and preferences of the person, including the right to take risks and make mistakes."* (United Nations Committee on the Rights of Persons with Disabilities, 2014 (1), paragraph 22)

For example, in the OPAN submission on capacity, guardianship and supported decision-making to the Royal Commission into Aged Care Quality and Safety (Aged Care Royal Commission), the ACT Disability Aged & Carer Advocacy Service Inc. notes that:

"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." (OPAN, 2020 (4), p.11)

Elder abuse is also prevalent in aged and health care institutions which may adopt overly paternalistic and ageist attitudes with the justification that they are acting in the 'best interests' of the individual. The OPAN submission to the Aged Care Royal Commission provides Sach's story as an example of such abuse by a service provider and enabled through a guardianship order (reproduced in Box 1).

Furthermore, institutions and individuals can exert abuse by continually questioning the decision-making ability, or the decisions made by, older people and those with suspected or diagnosed cognitive impairments. Although this is not explored in many abuse prevalence statistics, which tend to focus on the more overt signs of abuse (such as financial and physical).

Decision-making abilities as opposed to statements about capacity

Decision-making ability is used by OPAN to describe a person's ability to make a specific decision, or in rare and exceptional cases, a person's ability to make any decisions at all (e.g. if the person is in a coma). This is preferred to any statement about a person's 'mental capacity' or 'decision-making capacity' - terms often defined in legislation as a person's capacity to make decisions through "being able to understand, to retain, to use or weigh relevant information and to communicate one's decision" (7) (see, for example, the ACT *Mental Health Act 2015*).

However, mental capacity is often conflated with mental illnesses, psychosocial disabilities, communication ability, and memory loss. This leads to blanket statements about a person's overall 'capacity' when they are often able to make a range of decisions that affect their day-to-day lives. To avoid confusion, OPAN believes that the term mental capacity should be avoided except in rare circumstances where an overall lack of mental capacity can be defined. Otherwise, the varying decision-making abilities of a person should be described in a context-by-context manner with detailed rationale as to how this ability was assessed.

The Australian Law Reform Commission explored issues relating to the use of the term 'ability' versus 'capacity', stating that:

"Even the word 'capacity' may carry some of the connotations of previous times. 'Capacity' is regularly confused with 'legal capacity', and 'legal capacity' is regularly conflated with 'mental capacity'. To avoid such confusion and to direct reform towards

supported decision-making, the ALRC uses the word 'ability'—and emphasises that the focus should be on assessing how the individual can be supported to exercise their ability." (ALRC, 2014 (8) paragraph 2.50)

Best interpretation of will and preferences as opposed to best interests

OPAN supports the implementation of 'best interpretation of will and preferences' as opposed to 'best interests' as outlined here:

"Where, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the "best interpretation of will and preferences" must replace the "best interests" determinations. This respects the rights, will and preferences of the individual, in accordance with article 12, paragraph 4. The "best interests" principle is not a safeguard which complies with article 12 in relation to adults. The "will and preferences" paradigm must replace the "best interests" paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others." (United Nations Committee on the Rights of Persons with Disabilities, 2014 (1), paragraph 21)

The implementation of 'best interpretation of will and preferences' not only ensures that older people enjoy the right to legal capacity on an equal basis with others, but also provides a necessary clarity of terminology to guide supporters and substitute decision-makers.

Criteria used in assessments of decision-making abilities must be continually revised and improved

"The concept of mental capacity [defined as an ability to make decisions] is highly controversial in and of itself. Mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity." (United Nations Committee on the Rights of Persons with Disabilities, 2014 (1), paragraph 14)

Assessments of a person's ability to make decisions is often based on "being able to understand, to retain, to use or weigh relevant information and to communicate one's decision" (7). For example, under the ACT *Mental Health Act 2015*, the 'Meaning of decision-making capacity' is defined under Section 7(7) as:

"[…] a person has capacity to make a decision in relation to the person's treatment, care or support for a mental disorder or mental illness (decision-making capacity) if the person can, with assistance if needed—

a) understand when a decision about treatment, care or support for the person needs to be made; and
b) understand the facts that relate to the decision; and
c) understand the main choices available to the person in relation to the decision; and
d) weigh up the consequences of the main choices; and
e) understand how the consequences affect the person; and
f) on the basis of paragraphs (a) to (e), make the decision; and
g) communicate the decision in whatever way the person can."

Another example is provided by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (9) which proposes in Reform Proposal 5:

"A person has decision-making ability if they are able to make a decision with practical and appropriate support, and at the time when the decision needs to be made:

• understand the relevant information

• understand the nature of the decision and the consequences of making or failing to make that decision

• retain the information to the extent necessary to make the decision

• use the information or weigh it as part of the decision-making process

• communicate the decision in some way. […]"

Some decision-making ability assessment guidelines have included criteria related to the outcome of the decision and whether or not it is in the 'best interests' of the person or a decision they would have made in the past. However, the breaches of legal rights, including dignity of risk, in this approach are outlined in the quote of Dr Mary Donnelly by the Australian Law Reform Commission:

"Respect for the liberal principle of autonomy requires that external factors, including the outcome of the decision reached and the degree of risk assumed, are irrelevant to the determination of capacity. … [R]espect for autonomy is premised on allowing each individual to determine for herself what is good. Therefore, whether or not a person's decision complies with other people's perception of 'the good' is irrelevant to whether the person has capacity. In the words of the Law Commission [of England and Wales], according a role to the nature of the decision reached is inappropriate because it 'penalises individuality and demands conformity at the expense of personal autonomy'." (ALRC, 2014 (8) paragraph 3.49 and reference therein)

However, researchers have shown that these guiding criteria can be difficult to rationalise and apply in practice. A typology of more nuanced 13 capacity rationales

was developed based on 131 Court of protection and Court of appeal cases in England and Wales between 2008-2018 (7).

Legally appointed supporters

OPAN supports the statement by the United Nations Committee on the Rights of Persons with Disabilities that:

> *"Legal recognition of the support person(s) formally chosen by a person must be available and accessible, and States have an obligation to facilitate the creation of support, particularly for people who are isolated and may not have access to naturally occurring support in the community. This must include a mechanism for third parties to verify the identity of a support person as well as a mechanism for third parties to challenge the action of a support person if they believe that the support person is not acting in accordance with the will and preferences of the person concerned"* (United Nations Committee on the Rights of Persons with Disabilities, 2014 (1), paragraph 29(d))

Legal capacity should not be conflated with decision-making ability

Legal capacity is the ability to be able to exercise legal agency and be a holder of rights and should not be conflated with decision-making ability. Box 3 provides an example from an OPAN advocacy network where legal capacity was conflated with decision-making ability, which in turn was conflated with a memory impairment. For example, under the Convention of the Rights for People with Disabilities; legal capacity cannot be denied or limited based on a person's actual or perceived deficits in their mental capacity (defined as decision-making ability), as would be the case if a substitute decision-maker was put in place because a person was found to be lacking in their ability to make decisions (1).

Kuma's Story

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.

Reproduced from OPAN submission on capacity, guardianship and supported decision-making to the Royal Commission into Aged Care Quality and Safety prepared by the ACT Disability Aged & Carer Advocacy Service Inc., 2020.

"In most of the State party reports that the Committee has examined so far, the concepts of mental and legal capacity have been conflated so that where a person is considered to have impaired decision-making skills, often because of a cognitive or psychosocial disability, his or her legal capacity to make a particular decision is consequently removed. […] Article 12 [of the Convention on the Rights of Persons with Disabilities] does not permit such discriminatory denial of legal capacity, but, rather, requires that support be provided in the exercise of legal capacity." (United Nations Committee on the Rights of Persons with Disabilities, 2014 (1), paragraph 14)

The United Nations Committee on the Rights of Persons with Disabilities also highlights the importance of not conflating legal capacity and mental capacity in the context of deciding whether or not a person needs support to exercise legal capacity:

> *"The provision of support to exercise legal capacity should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity."* (United Nations Committee on the Rights of Persons with Disabilities, 2014 (1), paragraph 29(i))

The reality of this distinction is experienced by the OPAN network advocates who provide necessary support for older people to exercise their legal capacity even though many of these people needing support do not have any impairments in their decision-making abilities.

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OPAN Older Persons Advocacy Network

OPAN member organisations by state or territory:

ADACAS ADVOCACY

Advocacy Tasmania

ERA Elder Rights Advocacy
Supporting your right to quality care

Seniors Rights Service

Darwin Community LEGAL SERVICE

ADAAustralia
Your aged and disability advocates

aras
aged rights advocacy service inc.

Advocare
Empowering People

CatholicCare NT

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