



SUPPORTED DECISION- MAKING IN AGED CARE

A Policy Development
Guideline for Aged Care
Providers in Australia

Second Edition

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FOREWORD

“

Older people receiving aged care services have the same rights as any person to full and effective use of his or her personal, civil, legal and consumer rights. This is underpinned by the presumption that all adults have the right to make decisions that affect their life and to have those decisions respected. The presence of cognitive impairment is not a reason to exclude someone from decision-making.



Incoming Aged Care Quality Standards provide a framework for incorporating supported decision-making into an aged care service provider's practices and improve outcomes for consumers of services.

Our experience has shown that service provider performance in this area can vary greatly. Where it is done well consumers are supported to make meaningful choices and enabled to live the life they choose. Where it is not seen as a priority this inattention can increase the risk of undue influence or at worst abuse.

I commend the work of the Cognitive Decline Partnership Centre in developing the 'SUPPORTED DECISION-MAKING IN AGED CARE: A Policy Development Guideline for Aged Care Providers in Australia'. These important guidelines address the day to day question that we see playing out in aged care settings all over Australia. How can providers of aged care services support people with cognitive impairment to make and communicate decisions that affect their lives? It provides an evidence-based framework for providers to develop policy and processes and guide staff in an approach that will enable them to involve, listen to, and respect the views of the person, and seek to accommodate them.

”

A handwritten signature in black ink, appearing to read 'Nick Ryan', with a stylized flourish at the end.

Nick Ryan

Chief Executive Officer, Australian Aged Care Quality Agency

BACKGROUND

Growing attention on the United Nations Convention on the Rights of Persons with Disabilities, and Australia's international obligations as signatory to this Convention, means that there will be increasing attention on matters relating to consent, decision-making capacity and 'supported decision-making'.

Following a review of legal capacity and equal recognition before the law among people with disabilities, with reference to the United Nations Convention on the Rights of Persons with Disabilities, the Australian Law Reform Commission (ALRC) released a report in 2014. The Report "Equality, Capacity and Disability in Commonwealth Laws", included four key Decision-Making Principles, which provide a framework for recommended reviews of state, territory and Commonwealth legislation.[1]



The ALRC National Decision-Making Principles are likely to feature prominently in future reviews of legislation in this area.

However, supported decision-making is not only a legal concept – it occurs on a daily basis in aged care contexts, as well as in the broader community.

The increasing prevalence of dementia among aged care recipients, and growing focus on Consumer-Directed Care, makes it important to develop policies and practices that will provide maximal support for care recipients' abilities to participate in decision-making.

In 2016/17, seven aged care organisations across Australia participated in the first phase of a Cognitive Decline Partnership Centre project on supported decision-making in dementia, through the 'Understanding Policies of Residential and Community Care Organisations relating to Supported Decision Making' project. In this Policy document, we report on key findings from policy analysis and consultation with Australian aged care providers, taking the ALRC National Decision-Making Principles as a guiding framework.

THE NATIONAL DECISION-MAKING PRINCIPLES ARE:

- **PRINCIPLE 1:** All adults have an equal right to make decisions that affect their lives and to have those decisions respected;
- **PRINCIPLE 2:** 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 3:** The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives;
- **PRINCIPLE 4:** Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

It is acknowledged that some state/territory and Commonwealth legislation does not currently comply with the National Decision-Making Principles. However, incoming Quality Standards for aged care provides a framework for incorporating supported decision-making into policy and practice. Our research has shown that aged care providers currently have a range of policies relating to different aspects of decision-making (for example Capacity Assessment, 'Choice and Decision-Making', Risk Assessment, Restraint, Palliative Care and Advance Care Planning). We also observed differences between aged care providers in the issues highlighted in their policies, and approaches taken in implementing these policies. The aim of this document, therefore is to provide a generic, 'forward-looking' Policy Guideline, to assist aged care providers who choose to base their own policies on the National Decision-Making Principles.

In this **Policy Guideline document**, we:

- Describe key aspects of the National Decision-Making Principles, with specific attention to factors relevant for aged care providers across Australia
- Provide an Action Plan for policy development, which includes a range of practical tools:
 - **a self-assessment Tool** for aged care providers to assess their current policies; and
 - **a case study** 'Robin' which can be used in interactive exercises with aged care staff;
 - **a Model Policy Framework** for consideration by aged care providers to assist in reframing current policy settings

KEY TERMINOLOGY

RIGHTS-BASED APPROACH TO DECISION-MAKING: an approach that is centred on the rights of the person concerned. Such an approach begins with the presumption that all adults have the right to make decisions that affect their life and to have those decisions respected. This right to make decisions is seen in the context of the person's other rights (e.g. safety, shelter, privacy) and the rights of others.

SUPPORTED DECISION-MAKING: the process of enabling a person who requires decision-making support to make, and/or communicate, decisions about their own life. The decision-making is supported, but the decision is theirs.

REPRESENTATIVE DECISION-MAKING: when a representative is appointed to make decisions for a person who requires decision-making support. This is a last-resort process, and the representative should be directed by the will, preferences and rights of the person.[2] That is, they should do whatever they can to support the person to make their own decision, or if this is not possible, use a 'substituted judgement' approach, rather than a 'best interests' approach.

BEST INTERESTS: historically, this term has been used to describe decisions made by others that are motivated by what they think is best for the person.

SUBSTITUTED JUDGEMENT: this term refers to decisions made by others that are motivated by 'what the person would have wanted', had they been able to make the decision themselves.

WILL AND PREFERENCE: refers to the wishes of the person, which are informed by their established values, as well as their more current interests and desires. These can be either express (verbal or written) or implied. This is different from a person's 'best interest' as it focuses on the wishes of the person as expressed by them, or where this is not possible, inferred by those who know them well.

FUNCTIONAL CAPACITY ASSESSMENT: the functional approach to capacity assessment focuses on the functional decision-making abilities relevant to a specific decision, at a specific time. It is focused on identifying the support needs of the person, in order that their will, preferences and rights can be given effect. It is not dependent on whether the person's decision is 'wise' or 'unwise', or the presence of a particular disability or condition.[3]

NATIONAL DECISION-MAKING PRINCIPLES

The National Decision-Making Principles are recommendations from the ALRC, and provide a framework for reviews of state, territory and Commonwealth legislation. These Principles should not be confused with the various Principles (e.g. *User Rights Principles 2014*) which are already legislated under the *Aged Care Act 1997*.

Principle 1: All adults have an equal right to make decisions that affect their lives and to have those decisions respected.



This Principle recognises that making decisions about one's own life and having those decisions respected is an essential right of each person, and demonstrates that the person is valued in society. This right is to be enjoyed by all adults, including those with disabilities such as cognitive impairment. It also recognises that in exercising this right, the person may choose to delegate or abstain from decision-making.

This over-arching Principle leads to a number of recommendations relating to decision-making:

- A person's decision-making ability is to be presumed, and the presence of cognitive impairment is not a reason to exclude someone from decision-making. Policies will adopt a rights-based approach, guiding staff in the approach and processes that will enable them to involve, listen to, and respect the views of the person, and seek to accommodate them as is possible and reasonable;
- The policy will provide guidance on enabling a process where the person wishes to involve significant others in their decision-making, or to delegate the decision-making to others;
- The policy will recognise the threat to a person's sense of self when their decision-making ability is challenged, and thus position any assessment of ability as a last resort, requiring a valid trigger;
- When assessment of a person's decision-making ability is required, the policy will outline the need to utilise a functional approach, focused on assessing the person's understanding of the context, choices and consequences of the specific decision to be made, and understanding what supports might be required to make the decision. It should not involve a judgement on the perceived wisdom or outcome of the person's decision;
- The policy will outline the domains of decisions (e.g. financial, healthcare, lifestyle) and the functional abilities that would typically be relevant for decision-making in these different domains. This guidance should not be implemented prescriptively, but should inform the focus of any support or assessment of decision-making ability;
- The policy will outline the role, skills and knowledge of those undertaking assessments of decision-making ability;

- As decision-making ability can fluctuate in response to changes in a person's health and well-being, or in different settings, the policy will outline the importance of choosing the best time and place for the assessment. It may be necessary to repeat assessments when the decision is significant to the person's health or well-being, or where the decision may have a risk of harm;
- The policy will outline the process to be followed when a person refuses to engage in an assessment or discussion about a decision.

Principle 2: 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.

This Principle focuses on access to support, and the types of support that are provided to enable residents or clients to communicate, participate in decision-making, and ultimately, make decisions. Aged care providers should consider the role of policies in educating staff in the area of providing support, and clarifying the role of 'supporters'.

The implications of this Principle, relating to supported decision-making, would include:

- Acknowledgement of how existing or potential supports might be relevant in supporting a person's decision-making ability, in particular their ability to communicate a preference;
- Prompts to staff to consider contexts and/or interventions which can help support a person's decision-making ability;
- Guidance on the principles and practical aspects of providing support for decision-making;
- Clarifying the processes involved for different types or domains of decision-making, and who might be involved as a supporter in each decision;
- Clarifying the role of 'supporters' and 'representatives' with respect to the organisation and the client or resident;
- Clarifying the role of advocates (professional or informal) with respect to the organisation and the person being advocated for.

Principle 3: The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

This Principle focuses on a person's will and preference, including how these are elicited, and how they should inform and direct decision-making within a broader 'rights paradigm'. It is important to note that just because a person may lack 'decision-making capacity' (even with assistance), this does not automatically justify representative decision-making or overriding the person's will and preference. The importance of the 'rights paradigm' is in providing a framework for working through different approaches to respecting a person's will and preference, while also considering the person's other rights, and the rights of other residents, clients and staff.

The implications of this Principle, relating to will, preferences and rights directing decision-making would include:

- Prompts for staff to consider contexts and/or interventions which can assist in clarifying a person's will and preference;
- Clear guidance on decision-making processes when a person's will and preference is associated with risk, and development of a decision-making tool within the policy which begins with a presumption of giving weight to a person's will and preference;
- Clear guidance on decision-making processes when a person's will and preference is not known or ascertainable, including the status of their prior documented wishes, advance directives, and the role of representatives;
- An explicit set of Principles for representative decision-making to ensure that this is only used as a last resort and that the representative should apply a 'substituted judgment standard', making the decision that the person would have wanted;
- Content relating to the principles underpinning representative decision-making, so that it functions in a way that gives weight to a person's will and preferences;
- Clarification of the roles of supporters, representatives, advocates (professional and informal) and enduring attorneys/enduring guardians with respect to supported and/or representative decision-making.

Principle 4: Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

This Principle focuses on the safeguards that are in place to ensure that decisions made with support, or by representatives, do not lead to undue influence or abuse. Where a person's will or preference is overridden (e.g. through substitute decision-making), or where restrictive practices are implemented, these should be 'last resort' and monitored to ensure that these processes do not lead to abuse.

The implications of this Principle, relating to 'appropriate and effective safeguards' for those who require decision-making support would include:

- Recognition that a person's autonomy, and respect for their will and preference, is a key right, which is also balanced with other rights – policies in this domain should strike a balance between respect for the individual's autonomy and the protection of their other rights;
- Clarification of the role of 'representative' with consideration of the relevant pieces of legislation, including both Commonwealth and state/territory legislation;
- Clear guidance on the processes to follow when a staff member has concerns that a representative is acting in ways that appear at odds with respect for the person's will, preferences and rights;
- Clear guidance on the process to follow when a person has not expressed any wishes regarding end of life choices, and has since been judged to lack decision-making capacity to participate in ongoing decision-making or advance care planning. If the Person Responsible cannot complete an 'Advance Care Plan' under these circumstances guidance should inform staff as to the processes to be followed;
- Guidance for staff on organisational processes relating to the broader process of advance care planning, including any (non-binding) advance care planning which might occur on behalf of a resident/client who has impaired decision-making capacity;

- Guidance to staff that Advance Care Directives and/or Advance Care Plans should only be invoked when the resident/client is unable to make 'this decision' at 'this time';
- Clinical governance processes to ensure that all forms of restraint (physical, chemical, environmental, psychological and emotional) are used only as a last resort, in a least restrictive form for the minimum time possible and subject to review;
- Reference to the relevant Guardianship Board/Tribunal and applications to the Board/Tribunal by those persons who have a 'proper interest' in the person's care, where appropriate;
- Clear instructions on when and what documents can be destroyed, in compliance with the relevant legislation;
- Systematic review mechanisms to ensure that all policies remain consistent and are compliant with the relevant and current legislation;
- Guidance on the need to continually update policies to ensure regulatory compliance and in keeping with the person's current wishes;
- Consistent terminology across policy documents.



AN ACTION PLAN FOR **POLICY DEVELOPMENT**

STEP 1

SELF-ASSESSMENT AUDIT TOOL

This self-assessment tool was designed by the research team, and is provided here, to enable aged care providers to undertake their own ongoing reviews of policy compliance. This tool is designed to be generically applicable to policy and procedure documents relating to healthcare and lifestyle decision-making for aged care providers across Australia.

| PRINCIPLES | AREAS FOR ACTION | MAPPING TO STANDARDS |
|---|---|-------------------------------|
| PRINCIPLE 1: All adults have an equal right to make decisions that affect their lives and to have those decisions respected | | |
| 1A. Is there a published policy/procedure for assessing decision-making capacity? | Presence of a specific policy/procedure, approved for use within the organisation. | |
| 1B. Are rights-based or functionalist criteria applied for capacity assessment, as opposed to 'status' criteria (i.e. based on the presence of a diagnosis) or 'outcome' criteria (i.e. based on a judgement about the perceived wisdom of the person's decision)? | Description of decision-making process adopts an explicit rights-based approach (the person has a right to make their own decisions and have them respected) or refers to using a 'functional' approach to capacity assessment (the person is assessed in the context of the decision itself, focusing on their functional ability to understand the nature of this decision, along with any support they may require to make decisions). Either approach would promote the person's decision-making rights, and not discriminate on the basis of a person's disability.[4] | 1.3; 1.4; 3.1(a); 3.1(b); 3.4 |
| 1C. Are time- and decision-specific criteria applied for capacity assessment? | Explicit reference to decision-making capacity being specific to a time and a decision, and the assessment of decision-making capacity being separate from the decision the person wants to make.[5] | 1.3; 3.4 |
| 1D. Are tasks and professional roles in capacity assessment clearly defined? | Guidance or direction as to the key tasks involved, any prescribed procedures (e.g. 'six step capacity assessment approach') and who is responsible for undertaking these tasks. | 7.3; 7.4 |

| | | |
|---|--|-----------------------|
| 1E. Does the policy/procedure ensure that capacity assessment occurs in an optimal context? | Requirement that staff give consideration to the contextual factors that might influence the person's performance on a capacity assessment (e.g. time of day, obtaining consent, conducive environment etc) | 1.3; 2.3(a); 2.3(b) |
| 1F. Is the capacity assessment considered in the context of the person's current supports? | Requirement that the capacity assessment considers more than just results on a test, but also considers under what situations, or with what supports, might the person be more able to make a decision. | 1.3; 2.3(a); 2.3(b) |
| 1G. Is a judgment of incapacity preceded by attempts to support the person? | Requirement that staff make attempts to provide relevant supports which might assist a person in making a decision, prior to a determination that the person cannot make the decision. | 1.3 |
| PRINCIPLE 2: 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 | | |
| 2A. Are staff required to provide support for the person's decision-making capacity? | High level policy recognition that people should be enabled and/or supported in making decisions.[6] | 1.3 |
| 2B. Are the nature of any supports offered described? | Specific description of techniques that can be used to assist residents/clients in decision-making, and their application in different scenarios. | 1.3; 1.4; 1.5; 2.4 |
| 2C. Does the policy/procedure give recognition to the role of a supporter? | Clear recognition of how the "role of persons who provide decision-making support" is "acknowledged and respected".[7] This will include the rights and responsibilities of family members, carers and advocates (informal or professional) in relation to the organisation. | 1.3; 6.1; 6.2; 8.3(a) |
| 2D. Can support constitute an alternative to substitute decision-making? | Guidance or direction for staff as to whether, or how, a person's supportive arrangements can constitute an alternative to substitute decision-making. | |

| PRINCIPLE 3: The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives | | |
|--|---|--------------------------|
| 3A. Is the weighing of a person's expressed 'will and preference' against other interests (e.g. 'best interest', rights of others) consistent with ALRC Principles? | For a person who requires decision-making support, staff are required to give weight to the person's currently or previously expressed 'will and preference', unless this is unlawful or significantly compromises their other rights (e.g. right to safety). In some cases the rights of others may also be a relevant consideration. | 1.3; 1.4; 8.4(c)) |
| 3B. When a person's will and preference contradicts their other rights, is the policy approach consistent with ALRC Principles? | For a person who requires decision-making support, in resolving conflicts between their will and preference and other interests, staff are guided or directed to apply a rights-based approach. This starts with a presumption of giving weight to the person's 'will and preference', with consideration of any significant conflicts with their other rights. | 1.3; 1.4; 8.4(c) |
| 3C. Can a person's 'will and preference' be expressed non-verbally? | Tools and strategies are employed to facilitate alternative or augmented communication (e.g. use of pictures, assistive technology, 'talking mats'), so that a person can communicate "by any means that enable them to be understood". | 1.3; 2.3(a); 2.3(b); 3.4 |



| | | |
|---|--|---------------------------------------|
| 3D. What is done when a person's 'will and preference' cannot be determined? Is this consistent with ALRC Principles? | In cases where there is no way of ascertaining a person's current will and preference, their previous wishes (where appropriately documented) should be respected. If these are not available, an authorised substitute decision-maker should make a decision which adopts a 'substituted judgement' approach, attempting to 'stand in the shoes' of the person and make the decision which they would have made, had they been able to express a preference. Failing this, "the default position must be to consider the human rights relevant to the situation". | 2.2; 2.3(a); 3.4; 3.5; 8.3(a) |
| PRINCIPLE 4: There should be appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence | | |
| 4A. Do existing policy/procedures define how supportive or substituted decision-making arrangements should be monitored? | Guidance or direction for staff on processes to follow if there is concern about decision-making (e.g. reporting of undue influence or manipulation). | 2.3(a); 2.3(b); 8.4(b) |
| 4B. Do existing policy/procedures define how staff will ensure decisions made by a person are free of undue influence? | Guidance or direction for staff as to how they might monitor decision-making processes, assess for signs of concern and intervene if appropriate. | 1.3; 1.5; 1.6; 2.3(a); 2.3(b); 8.4(b) |
| 4C. If a person's 'will and preference' is overridden, do existing policies/procedures ensure this is a last resort, tailored and proportionate to risk? | A clear description of the principles to be employed by staff in managing situations in which a person's will and preference is overridden (e.g. by substitute decision-making) to ensure that this approach is taken only as a last-resort, in ways that are appropriately tailored to the person (e.g. with consideration of other options which might be satisfactory for them) and only to the extent that this will or preference impinges on other key rights (e.g. personal safety or rights of others). | 1.4; 3.1(a); 3.1(b); 3.2; 8.5(b) |
| 4D. Where restraint is used, do existing policy/procedures ensure this is a last resort, tailored and proportionate to risk? | Clear and comprehensive definitions of restraint or restrictive practices. Presence of procedures which ensure careful assessment, multi-disciplinary input, trials of other non-restrictive interventions, and that any restrictive practices applied are used for the shortest possible time, in the least restrictive way, and subject to regular review. | 3.1(a); 3.1(b); 3.2; 8.5(b) |

STEP 2-1

INTERACTIVE CASE STUDY

ROBIN – CHAPTER 1

Robin is a 78-year-old recently widowed lady who lives at home alone. At present she is coping well, and undertaking a number of regular activities with family and a few close friends in the neighbourhood. Robin was diagnosed with vascular dementia two years ago, after experiencing mild subjective memory concerns over a number of years. Since then she has experienced a progressive decline in communication, with occasional marked difficulties in word-finding which impacts on her ability to socialise or manage shopping, particularly if she is anxious.

Robin has two children, Murray and Jessica. Murray lives nearby and provides some assistance with weekly shopping and household maintenance, but is struggling financially, and sometimes needs to stay with Robin at her house. Jessica lives two hours away and has a busy full-time job which includes occasional travel commitments. Robin is closest to Murray and he appears to be able to interpret her needs most clearly, particularly when she is confused, or struggling to communicate. Jessica is appointed as Robin's attorney (through an Enduring Power of Attorney form) which is not to come into effect until Robin has lost decision-making capacity.

Robin receives a Level 2 Home Care Package. Through discussions with Robin and Murray, the Coordinator of Robin's home care service package understands that Robin is concerned about what would happen if she required more support at home, or "was unable to cope". She feels strongly that she wants to remain at home and see her children regularly, but also talks about "not wanting to be a burden on them" with additional responsibilities.

REFLECTIVE QUESTIONS:

- **How could staff take a supported decision-making approach relating to this decision?**
- **Who would be involved?**
- **What would help?**

FACILITATOR DISCUSSION GUIDELINES:

A supported decision-making approach would start by providing support for Robin to make a decision for herself. If all reasonable and practicable supports have been tried unsuccessfully, or if Robin prefers to delegate the decision to others, then a last resort would be to use a representative. The representative should still be directed by what they know (or can find out) about Robin's wishes. Importantly, it should be recognised that while Robin has nominated Jessica as her enduring power of attorney, this applies to financial matters, and does not give Jessica the authority to make healthcare or lifestyle decisions on Robin's behalf.

Generate discussion about what Robin would need to understand, in order to make a decision about her care package. Robin's communication difficulties do not mean that she 'lacks capacity' or cannot be involved in decision-making. Difficulties in word-finding and associated anxiety could be addressed through meeting in a safe, familiar environment, involving trusted family members or friends and employing communication aids (e.g. visual cues, photographs and/or written material if appropriate). Robin should have input into who is involved in the decision-making process. Both Murray and Jessica should be included if possible. Staff can suggest a family-based approach to decision-making, while providing support and advocacy, to ensure that family members understand that their role is to assist Robin in expressing her wishes.

STEP 2-2

INTERACTIVE CASE STUDY

ROBIN – CHAPTER 2

Twelve months later, following periods of confusion at home culminating in a number of falls and a hospital admission, Robin has experienced an overall deterioration in her health and has expressed that she feels unsafe at home on her own. Murray has recently moved back in with Robin, and is assisting with some of the washing, meals and appointments. Robin and Murray both seem happy with this. Jessica has tried to persuade Robin to apply for a place in a residential care facility. Jessica thinks that Murray is living in Robin's house to suit his own needs, and she would like to see the property sold to pay for Robin's aged care fees. Robin says that she is happy to look at a place in residential care, but still wants to stay at home "while she can cope".

The visits to some nearby facilities go smoothly, and a few months later a place becomes available. Jessica tries to convince Robin to accept the admission. At this point Robin becomes very anxious and says she definitely doesn't want to leave home. Both Murray and Jessica try to explain that the place might not be available in the future, but Robin does not appear to understand and remains anxious and fixated on not being "sent away". When Jessica tries to raise the discussion again the next day, she gets the same response.

Jessica thinks that they should accept the place, and Robin would "get used to it once she's there". Murray thinks that they can continue with the current living arrangements, and seek additional home support.

REFLECTIVE QUESTIONS:

- **How could staff take a supported decision-making approach relating to this decision?**
- **Who would be involved?**
- **What would help?**

FACILITATOR DISCUSSION GUIDELINES:

A supported decision-making approach would respect Robin's will and preference in the decision-making. It appears that this situation is very distressing for her, and it is uncertain whether she is actually able to fully understand the nature and consequences of the decision. However the residential care facility need an answer, hence a decision of some sort has to be made. If Murray or Jessica are responding as representatives for Robin, they should be directed by her 'will and preference'. Robin has clearly stated that she would like to remain at home while there are other people available, and there is nothing preventing this in the current situation. Murray is reflecting a view that is in line with Robin's will and preference, and is acting consistently with Principle 3. It is only justifiable to override Robin's will and preference if this results in a significant risk of harm to herself or others, and then only in ways that are the least restrictive, tailored to the situation, proportionate to the need, and subject to review.

In this case staff could assist by explaining the further options for home care services to Jessica and alleviating her concerns. They can also be aware of the potential conflicts of interest for Murray (access to free accommodation) and Jessica (financial interest in sale of house) and work to ensure that Robin's preferences are voluntarily expressed, and that the childrens' wishes do not unduly influence her.

REFLECTIVE QUESTIONS:

Principle 1: All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

- How can aged care policy and staff actions contribute to ensuring Robin has an “equal right to make decisions about her life, and have those decisions respected”?
- What factors might be relevant to assessments of Robin’s ability to make decisions about her healthcare, lifestyle and/or other matters?

Principle 2: 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.

- Who is best placed to support Robin’s decision-making, and how should this person’s role be defined in relation to the organisation, and people in other roles (e.g. substitute decision-makers)?
- What actions can be taken to provide support for Robin in making decisions?

Principle 3: The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

- How can aged care policy and staff actions contribute to ensuring that Robin’s ‘will, preferences and rights’ direct the decisions about her life?
- What happens if Robin’s will and preference conflicts with what Jessica or Murray thinks should happen?

Principle 4: Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

- How can aged care policy and staff actions contribute to ensuring that “appropriate and effective safeguards” are in place, and that abuse and undue influence are prevented?
- What are the risk factors for abuse and undue influence in this case, and what could be done to safeguard the decision-making process?

STEP 3

A MODEL POLICY FRAMEWORK

Given the Principles listed above, this section explores a potential framework and structure for Aged Care Provider policies, with the aim of achieving a practical compliance with the National Decision-Making Principles. Further systems will need to be established to fully implement these policies, through provision of education, data collection and compliance monitoring. Full, best practice implementation would likely also require advocacy and awareness-raising among other practitioner groups and the broader community. However, with respect to the four National Decision-Making Principles we would recommend aged care providers take the following approach:

PRINCIPLE 1:

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

KEY ACTION:

Develop a high-level policy document which conceptualises the organisation's approach to decision-making, capacity and consent

- As an overarching principle, participation in decision-making, and having one's will and preference respected, is conceptualised as a right. A rights-based approach to decision-making aligns with incoming Quality Standards and broader principles of dignity and person-centred care. An adult with decision-making capacity has a right to make and enact decisions, unless these are unlawful, or unreasonably impinge on the rights of others. An adult who lacks decision-making capacity still has a right to have their will and preference respected, with consideration and balance of their other rights and the rights of others.
- As a complementary principle, it should also be recognised that a person has the right to delay, defer or delegate decision-making to others, either by formal or informal means.

- If a person lacks decision-making capacity, this does not, on its own, justify excluding the person from decision-making or overriding their will and preference. We recommend adopting a presumption of respecting the person's current will and preferences, while considering their previously documented wishes, along with other rights, and the rights of others.
- With respect to decision-making, it would be recognised that:
 - people make decisions in response to meaningful choices and options;
 - people make decisions in differing contexts (e.g. relationships, environment, life situation, available resources) and that these contexts can support, or hinder, a person's ability to make decisions;
 - decisions take place over time, with each decision embedded in the broader narrative of a person's life;
 - decisions vary in complexity and risk, some are major while others are routine.
- Staff can work proactively to create contexts in which people experience meaningful choices and options, are enabled to participate in decision-making, and have their will and preference respected, to the maximum extent possible. Part of this includes working proactively with residents and clients to establish social histories, life-story work, care plans and advance care plans, as documentation which might assist in future decision-making scenarios. Everyday contexts, relating to social and spiritual activities, meals and personal care are also contexts in which people can experience meaningful choices and options.

PRINCIPLE 2:

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.

KEY ACTION:

Clarify the role of supporters, representatives and advocates with respect to the organisation and the individual client or resident, as well as the principles underpinning supported and substitute decision-making

Clarifying roles and responsibilities in decision-making will assist clients/ residents, family members, staff and other practitioners in effectively working together to make decisions which are consistent with the National Decision-Making Principles, as well as aligning with relevant Quality Standards.

- Define and provide recognition for the role of a ‘supporter’ in relation to the organisation and individual client or resident. Clarify that this person has the role of assisting the client or resident in their decision-making. Provide guidance as to how this person might function in their role (e.g. accessing the client or resident’s health information if they have permission).
- Define the role of ‘representative’ decision-maker in relation to the organisation and individual client or resident, to ensure that this type of decision-making takes place only as a last resort, and subject to safeguards and regular review.
- Ensure that representative decision-makers are aware of their responsibilities to respect the person’s will and preference wherever possible. Provide information for representative decision-makers about the ‘substituted judgement principle’, attempting to stand in the person’s shoes and make the decision that they would have wanted.
- Clarify the role of ‘advocates’ with respect to the organisation and the individual client or resident. This would include clear guidance on access to information and the nature of the advocacy relationship.
- Clarify that staff have a responsibility to provide support for a person’s decision-making capacity, and should have access to clear guidance (e.g. policies and procedures) relating to how this might be implemented in the context of different types of decisions (e.g. healthcare, dietary, activities, sexuality and intimacy). This could come in the form of more specific resources or interventions for staff relating to supporting a person with cognitive impairment (e.g. ‘Talking Mats’), as well as the relevant factors in making decisions in different domains.
- Consider developing targeted programs aimed at staff creating contexts in which communication can be supported and a person’s will and preferences elicited. This might include person-centred interventions like taking social histories or life-story work.

PRINCIPLE 3:

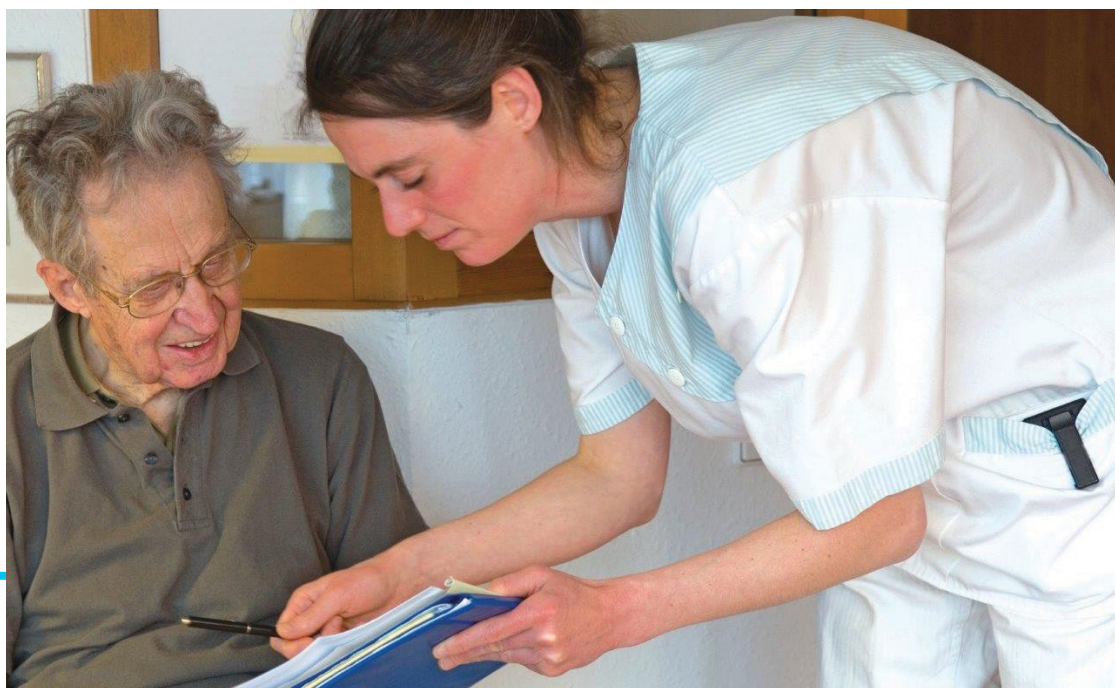
The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

KEY ACTION:

Provide a decision-making tool, to clarify processes relating to how staff may respect a person's will and preference in the context of risk

Risk is inherent in care provision, decision-making and everyday life. Equipping staff to appropriately manage risk, in the context of a presumption of respecting the client or resident's will and preference will promote an approach that is consistent with the National Decision-Making Principles, and incoming Quality Standards.

- Clarify that decision-making begins with a presumption of respecting a person's will and preference, unless this is unlawful or unreasonably impinges on the rights of others.
- If a person's will and preference involves some level of risk, this should be understood in terms of the person's capacity to foresee and understand this risk. A resident or client may require support from staff, supporters or advocates to understand risks and incorporate this into decision-making, as well as retaining this awareness over time. Where a person lacks decision-making capacity (despite having access to support) and is placing themselves in a situation of risk, then this may be a last resort situation which justifies the use of representative decision-making and/or the person's will and preference being overridden.



PRINCIPLE 4:

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

KEY ACTION:

Ensure that safeguards are in place to deal promptly with suspected abuse or undue influence

At an organisational level, aged care providers should work to equip staff in pre-empting, detecting and appropriately responding to suspected abuse or undue influence. In the context of decision-making this relates particularly to undue influence over a person's decision-making, or unnecessary restriction of the options available to them. This directly addresses Principle 4 of the National Decision-Making Principles, and is an important component of meeting relevant Quality Standards.

- Provide guidance for staff in relation to monitoring decision-making processes and assessing for signs of concern, particularly from the resident or client.
- Clarify processes for staff to follow if there is concern about a supported or representative decision-making process. This should include reporting pathways, and the need for documentation and communication to other members of the care team. This might include an initial process focused on mediation and dispute resolution, with guidance to refer the matter to a relevant tribunal if required.
- If representative decision-making is used, clarify the processes in place to ensure that this is used only as a last-resort, and in ways that respects the person's will and preference, through the use of a 'substituted judgement' approach.
- Embedding these decision-making principles into an overarching policy framework for decision-making will enable other relevant policies (e.g. advocacy, care planning and advance care planning, palliative care, risk assessment, restraint, sexuality and intimacy) to be informed by this overarching approach to decision-making across the organisation.
- Provide guidance for staff as to the decision-making processes to be followed where 'supporters' and 'representatives' are involved in a decision-making process. This may draw on communication skills in the area of facilitation or mediation.

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REFERENCES

1. Australian Law Reform Commission. *Equality, Capacity and Disability in Commonwealth Laws*. Sydney: 2014.
<https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>
2. Australian Law Reform Commission. *Equality, Capacity and Disability in Commonwealth Laws*, at 3-3. Sydney: 2014.
<https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>
3. Australian Law Reform Commission. *Equality, Capacity and Disability in Commonwealth Laws*, at 3.44-3.46. Sydney: 2014.
<https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>
4. Australian Law Reform Commission. *Equality, Capacity and Disability in Commonwealth Laws*, at 3.44-3.48. Sydney: 2014.
<https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>
5. Australian Law Reform Commission. *Equality, Capacity and Disability in Commonwealth Laws*, at 3-2(2)(c, d, f). Sydney: 2014.
<https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>
6. Australian Law Reform Commission. *Equality, Capacity and Disability in Commonwealth Laws*, at 3-2(1)(b). Sydney: 2014.
<https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>
7. Australian Law Reform Commission. *Equality, Capacity and Disability in Commonwealth Laws*, at 3-2(1)(c). Sydney: 2014.
<https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>

FURTHER RESOURCES

Australian Law Reform Commission. Equality, Capacity and Disability in Commonwealth Laws. Sydney: 2014. Retrieved 28/2/2018 from <https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>.

Darzens P, Molloy D and Strang D. Who can decide? The six-step capacity assessment process. Adelaide: Memory Australia Press, 2000.

Department of Health. Draft Aged Care Quality Standards. Canberra: 2017. Retrieved 28/2/2018 from <https://agedcare.health.gov.au/quality/single-set-of-aged-care-quality-standards>.

NSW Government Attorney General's Department. Capacity Toolkit. Sydney: 2008. Retrieved 28/2/2018 from http://www.justice.nsw.gov.au/diversityservices/Documents/capacity_toolkit0609.pdf.

SA Health Department. What is decision making capacity? Retrieved 28/2/2018 from <http://www.sahealth.sa.gov.au>.

Sinclair C, Field S, Williams K, Blake M, Bucks R, Aurret K, Clayton J, Kurrle S. Supporting decision-making: A guide for people living with dementia, family members and carers. Sydney: Cognitive Decline Partnership Centre, 2018. Retrieved 18/10/2018 from <http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php>

Victorian Office of the Public Advocate. *Side by Side: A guide for people wanting support to make decisions*. Melbourne: 2018. Retrieved 30/4/2018 from <http://www.publicadvocate.vic.gov.au/our-services/publications-forms/supported-decision-making-1/side-by-side-a-guide-to-appointing-supportive-attorneys>.

Victorian Office of the Public Advocate. *Supported decision-making in Victoria: A guide for families and carers*. Melbourne: 2017. Retrieved 30/4/2018 from <http://www.publicadvocate.vic.gov.au/our-services/publications-forms/supported-decision-making-1/supported-decision-making-guide-for-families-and-cares>.



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