

Supported Decision-Making in the National Plan on elder abuse

Consensus Recommendations



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Executive Summary

During October 2018 a Cognitive Decline Partnership Centre research team convened a forum aimed at generating consensus recommendations relating to the incorporation of supported decision-making in the National Plan on elder abuse. This day-long forum was independently facilitated, and involved 36 key stakeholders from a range of backgrounds and perspectives.

Based on discussion during the forum, and further consultation with participants in the weeks following the forum, ten key recommendations are made:

The National Plan:

- 1. must be human rights-based, acknowledging the importance of supported decision-making in maximising independence for older people;**
- 2. must recognise the value of older people, including recognising their experience as decision-makers, and therefore working to maximise their involvement in decision-making about their lives;**
- 3. should include key supported decision-making concepts and principles, using nationally consistent definitions and terminology;**
- 4. should recognise that decision-making occurs in a social and cultural context, and that supported decision-making needs to accommodate diversity and be sensitive to cultural factors;**
- 5. should 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 all stakeholders;**
- 6. should recognise the need for a significant 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 independence;**

- 7. in addressing elder abuse, must be inclusive of supported decision-making, and promote a decision-making process that is person-centred, individually-tailored, multi-disciplinary, multi-sectoral and collaborative;**
- 8. should identify appropriate funding and resourcing that may be applied to supported decision-making initiatives, with the aim of enabling meaningful choices for people and sufficient time to implement supported decision-making;**
- 9. should promote the embedding of supported decision-making principles and practices in all educational and training programs relating to those working with older people with decision-making disabilities;**
- 10. should suggest that governments only fund those services working with older people with decision-making disabilities where supported decision-making policies and practices are in place.**

This report will be submitted to the Council of Attorneys-General Working Group on Protecting the Rights of Older Australians, and made publicly available on the Cognitive Decline Partnership Centre website.

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Background

During August 2018 the Cognitive Decline Partnership Centre (CDPC) research team investigating ‘supported decision-making in dementia’ circulated invitations to a forum, which aimed to generate consensus recommendations for the inclusion of supported decision-making in the National Plan on elder abuse (‘the National Plan’).

The forum was motivated by a consultation paper circulated by the Council of Attorneys-General Working Group on Protecting the Rights of Older Australians (‘the Working Group’), which included a specific proposed initiative on ‘Building skills in supported decision-making’. The intention was to provide consensus recommendations on how this specific initiative might be implemented, or form part of the National Plan. The broader policy context for the implementation of supported decision-making includes Australia’s ratification of the Convention on the Rights of Persons with Disabilities,[1] and the Australian Law Reform Commission’s ‘Equality, Capacity and Disability in Commonwealth Laws’ report.[2]

The day-long forum took place on Monday October 15th, 2018. The forum involved 36 key stakeholders from a range of backgrounds and perspectives (see Appendix 1 ‘Participants’). The forum included a number of workshops and discussion sessions (see Appendix 2 ‘Program’), which were independently facilitated by Les Stahl (Facilitation Plus Australia Pty Ltd).

Forum Goals

The key goals of the forum were to:

1. **Bring together key stakeholders** (with research, policy and lived experience) to collate existing research and resources (from relevant work around Australia) as part of initiatives within the National Plan.
2. **Prioritise initiatives** that will contribute to optimal implementation of supported decision-making principles and practices in the National Plan.
3. **Agree on a set of recommendations** that can inform optimal implementation of supported decision-making principles and practices in the National Plan.

4. **Develop agreements on ongoing collaborative work** to address goals 2 and 3, including through collaborative use of relevant resources.

Forum Design

The forum was conceptualised by the CDPC ‘supported decision-making in dementia’ research team in partnership with ACT Disability, Aged and Carer Advocacy Service (ADACAS) and facilitator Les Stahl. In order to inform discussions, participants heard presentations from a person with lived experience of dementia, researchers engaged in ongoing work in supported decision-making, and key stakeholders with roles relevant to the broader implementation of supported decision-making for older people with decision-making disabilities.

Four facilitated workshops (one ‘breakout’ discussion involving five small groups, and three plenary discussions) were employed to achieve the forum goals, moving sequentially from collating and prioritising ideas, through to developing high-level recommendations and agreeing on ongoing collaborative approaches to further work in this area.

Following completion of the forum, a set of draft outcomes were circulated to forum participants, with invitations to comment further over a two-week period during late October 2018 (including an invitation to seek broader comments from within each participant’s organisation, membership and/or stakeholder groups). The CDPC research team coordinated this process of feedback and circulated the final report to participants, as well as to the CAG Working Group.

Elder Abuse

Elder abuse was defined using the World Health Organisation definition as “a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person.”[3] This included acknowledgement of the various forms of elder abuse, including financial, physical, psychological/emotional,

social and/or sexual, as well as that it can also be the result of intentional or unintentional neglect.

[Supported decision-making](#)

Supported decision-making was defined according to the United Nations definition as “the process whereby a person with a disability is enabled to make and communicate decisions with respect to legal matters.”[4] This included an acknowledgement of the distinction between ‘supported decision-making’ (the laws and frameworks that ensure full respect for a person’s rights, will and preference) and ‘support for decision-making’, the practical acts of help and assistance that might be provided to enable a person in making and communicating decisions, even in the absence of formal legal frameworks.[5] Forum participants recognised that supported decision-making is not required for (or wanted by) all older people. Instead it is relevant for those older people who have an impairment that results in a decision-making disability.

[Context and Update on the National Plan on elder abuse](#)

The Commonwealth Attorney General’s Department provided background context information including an update on the progress of the National Plan, in the form of a written summary. This is re-produced below:

Contextual Information

- The National Plan (the Plan) has been under development for several months and has involved the collective effort of the Commonwealth Attorney-General’s Department (AGD) and representatives from every state and territory government.
- The Council of Attorneys-General Working Group on Protecting the Rights of Older Australians (the Working Group) is continuing to progress development of a draft National Plan following consultations that took place earlier this year.

Supported decision-making in the National Plan

- The consultation paper, which we understand has been circulated to attendees, was designed to support further development of the Plan.

- AGD expects that the priority areas identified in the consultation paper may evolve.
- AGD notes that:
 - supported decision-making arrangements could be of great value to many older Australians, as they can protect older Australians and assist them to make good decisions about the things that affect them as they age.
 - substitute decision-making and supported decision-making can be examined as separate but related issues, noting that one does not supersede the other as they are used in distinct circumstances.
 - supported decision-making is an emerging model, and it may take time to establish comprehensive policies on areas such as assessing the decision-making capacity of an older person, or defining the role of a substitute decision-maker.

Update on Progress

- AGD undertook national consultations in July and August.
- Additionally, all states and territories also undertook their own jurisdictional consultations.
- A draft of the Plan is expected to be presented to the Council of Attorneys-General (CAG) at its next meeting on 23 November 2018.
- Although a draft of the Plan has already been progressed for consideration by the CAG, we are encouraged by the interest and discussions that this forum will generate.

The Forum Coordinator clarified that the Commonwealth AGD have not provided commitments to implement the recommendations arising from the forum, but have expressed interest in receiving the report relating to the discussion.

Thematic synthesis of facilitated group discussion

Through presentations, small group and plenary group discussions, a number of themes emerged, which informed ongoing discussion and consensus on the key recommendations relevant to supported decision-making for older people with decision-making disabilities.

Supported decision-making among older people with decision-making disabilities

Key observations and recommendations relevant to supported decision-making among older people with decision-making disabilities included:

- The person requiring support and their rights, will and preferences should be at the centre of all decision-making;
- The target audiences are diverse and diffuse, meaning that a broad approach is required, along with tailored approaches for specific communities;
- Need to reach people who are experiencing cognitive decline as early as possible, to enable a proactive approach and to identify, sustain and build support networks;
- People living with dementia described the importance of a relational approach to decision-making – interventions need to provide support for people in the context of their relationships wherever possible;
- The need to work within existing legal frameworks (don't wait for law reform) and to build on existing resources through partnership;
- Understanding (and working to address and challenge) the endemic nature of ageism in all settings.

Supported Decision-Making Resources

Key observations and recommendations relevant to supported decision-making resources included:

- Supported decision-making resources should be practical and easy to use and understand;
- Resources should avoid jargon, use everyday language and enable people to take action, by clarifying roles, offering 'step by step' approaches and identifying referral pathways and other sources of information;

- Supported decision-making resources should be accessible and known about, ideally consolidated and available in a central repository or ‘knowledge hub’;
- Supported decision-making resources should be available in a range of formats and media (e.g. online and hard copy, audio-visual, text) as well as in culturally appropriate forms, and translated into languages other than English;
- Those producing supported decision-making resources should work strategically and collaboratively, to build on existing resources and reduce duplication, while targeting specific populations who may require tailored resources (‘easy access to resources’ and ‘reducing duplication’ were key messages from consumer participants);
- Supported decision-making resources should be promoted to the public as a tool to enable control over their lives.

The Aged Care Sector

Key observations and recommendations relating to the context of the aged care sector with respect to supported decision-making:

- Supported decision-making is promoted by aged care sector peak bodies, including through high-level position statements;
- Both supported decision-making and substitute decision-making carry with it the responsibility to ensure that the wishes of the person (or what would be understood to be the wishes of the person), are respected, rather than what the wishes of the supporter or substitute decision-maker might be;
- Incoming aged care standards place a greater emphasis on consumer dignity, choice and control (particularly Standards 1 and 2). However aged care providers will be preparing to be accredited against all eight standards (by July 2019);
- Tools for the aged care sector in implementing supported decision-making include a ‘Policy Guideline’ (for managers and those developing policies) and a training package for staff, developed by the CDPC research team;

- The current climate (including Royal Commission into aged care sector) will likely make many aged care providers risk-averse.
- The aged care sector continues to face challenges in adequately resourcing care for a growing ageing population with increasing support needs.

Supported decision-making in the National Plan

Key observations relating to the inclusion of supported decision-making in the National Plan included:

- A high-level, principles-based approach would be preferable, as the majority of organisations and agencies responsible for delivering the components of the National Plan will be administered at a state and/or territory level.
- Considerations would include:
 - i. the preventative role of supported decision-making in reducing the incidence of elder abuse;
 - ii. the role of supported decision-making as part of a rights-based response to elder abuse; and
 - iii. the need for broader strategies in responding to elder abuse to be rights-based and inclusive of supported decision-making.

Key Supported Decision-Making Resources

Through collaborative discussion a range of resources, initiatives and partnerships were identified and collated. The detailed points raised within each small discussion group were recorded and made available to forum participants. A selection of key resources, initiatives and partnerships that are deemed to be particularly relevant for consideration in the National Plan are included below. Resource relevance was determined on the basis of topic area fit and accessibility (ideally freely available, presented in lay language and in accessible / multi-media formats).

[Victorian Office of the Public Advocate supported decision-making resources](#)

Materials available include:

- Supported Decision-Making in Victoria: A guide for family and carers;[6]
- Side by side: A guide for people wanting support to make decisions;[7]
- Role of the medical support person (brochure)

These resources are targeted to community members and include accessible explanations and some case studies. The materials are relevant to older people and those with cognitive impairment, though not particularly targeted towards these groups. The materials are particularly relevant to the Victorian context, in which there is a legal mechanism for appointing a ‘supportive attorney’ and a ‘medical support person’.

[Cognitive Decline Partnership Centre supported decision-making resources](#)

Materials available include:

- a guidebook targeted at community members living with dementia and/or family members and carers;
- a policy development guideline for aged care providers;
- a series of short videos exploring lived experiences of supported decision-making, including a feature video on enabling choice in the context of risk;
- a forthcoming single-page ‘helpsheet’ on supported decision-making;
- a half-day training package targeted at aged care staff;
- three webinar recordings;

These resources were co-designed with consumers in the context of a research project, and are particularly relevant for people living with dementia or related cognitive impairment.[8] A related CDPC project produced materials relevant for staff in the banking sector, to better understand powers of attorney and to detect and respond more effectively to financial elder abuse.[9]

[La Trobe University Support for Decision-Making Practice Framework](#)

This resource outlines a practice framework for assisting people living with cognitive disabilities to have greater control over their own lives, particularly in the context of participating in pre-planning, planning and implementation of support plans funded under the National Disability Insurance Scheme (NDIS).[10] The Practice Framework outlines key roles for decision supporters including

- i. Developing skills as decision-making supporters
- ii. Helping to build a network of supporters for a person
- iii. Building relationships with those who have no access to supporters

While this resource is targeted at those working within the NDIS, the practice framework provides a number of guiding principles that are relevant for those working with older people with decision-making disabilities.

[Capacity Australia Resources and Educational Tools](#)

Capacity Australia, a not for profit human rights charity,[11] have available a number of educational resources for health, legal and financial practitioners on both supported decision-making and elder abuse. These include:

- the ‘Capacity and the Law’ online text (free e-book);[12]
- a Banking Tool for staff in financial institutions to assist in detecting and responding more effectively to financial elder abuse.
- a guide to the integration of capacity assessment with supported decision-making for health practitioners – the ‘ASK ME’ approach (**A**ssess strengths and deficits, **S**implify the task, **K**now the person, **M**aximise the person’s ability, **E**nable participation).[13]
- the EMPOWERED project, a Dementia and Aged Care Services funded project using consumer choice and information principles to promote

autonomous and supported decision-making by people with dementia and their carers.[14]

NSW Government 'Capacity Toolkit'

This resource has been available since 2008 and is freely available online (small fee for hard copy).[15] The resource is targeted towards practitioners and provides a practice guide to capacity assessment, informed by ideas related to supported decision-making and broader rights-based approaches. This resource appears to be relatively well known about among health and legal practitioners.

Elder Abuse Action Australia

Elder Abuse Action Australia (EAAA) was launched on June 14, 2018 and is currently establishing a network of member organisations.[16] EAAA is also undertaking a scoping and feasibility study relating to the creation of a 'Knowledge Hub'. This work is currently underway, and may result in the creation of an online 'clearing house' for resources relevant for community members (including older people), practitioners and service providers.

It is proposed that policy leadership provided via the 'National Plan on elder abuse' could enhance efforts to adopt a consistent approach to implementing key supported decision-making resources and initiatives across Australia. Participants endorsed the view that a Knowledge Hub overseen by EAAA would be an effective means of consolidating relevant resources, perhaps through a dedicated 'supported decision-making' tab.

Key Recommendations

The following high-level recommendations from this forum were arrived at by consensus following plenary discussions. The recommendations are aimed at informing how the National Plan might be framed, in order to:

- i) facilitate the role of supported decision-making in preventing or minimising elder abuse;
- ii) ensure that any responses to elder abuse promote the inherent dignity and autonomy of older people, through respecting their rights, will and preferences;
- iii) ensure that any responses to elder abuse emphasises the person's right to be involved in decision-making and enables supported decision-making wherever possible.

The National Plan:

- 1. must be human rights-based, acknowledging the importance of supported decision-making in maximising independence for older people;**
- 2. must recognise the value of older people, including recognising their experience as decision-makers, and therefore working to maximise their involvement in decision-making about their lives;**
- 3. should include key supported decision-making concepts and principles, using nationally consistent definitions and terminology;**
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- 9. should promote the embedding of supported decision-making principles and practices in all educational and training programs relating to those working with older people with decision-making disabilities;**
- 10. should suggest that governments only fund those services working with older people with decision-making disabilities where supported decision-making policies and practices are in place.**

Participants agreed to these recommendations in principle, and endorsed their inclusion in the National Plan on elder abuse, as part of a community and key stakeholder informed response to the proposed initiative 'Building skills in supported decision-making'.

Appendix 1 – Participants

John Chesterman	Office of the Public Advocate (Victoria)
Anne Gale	Office of the Public Advocate (South Australia)
Christina Thompson	ACT Public Trustee & Guardian
Margaret Redmond	Office of the Public Advocate (ACT)
Belinda Morris	Commonwealth Department of Health
Isolde Kauffman	Commonwealth Department of Health
Theresa Flavin	Consumer Participant
Cate McCullough	Consumer Participant
Karine Shellshear	Consumer Participant
Kathy Williams	Consumer Participant
Fred Tanner	Consumer Participant (previous Chair of National Aboriginal and Torres Strait Islander Dementia Advisory Group)
Craig Gear	Older Person's Advocacy Network
Russell Westacott	Seniors Rights Service NSW (and Elder Abuse Action Australia Co-Director)
Diedre Timms	Advocare CEO (and Elder Abuse Action Australia Co-Director)
Dr Emma Campbell	Federation of Ethnic Communities' Councils of Australia
Annelise Van Deth	Aged Rights Advocacy Service South Australia
Cecilia Milani	Partners in Culturally Appropriate Care NSW/ACT
Cristina Giusti	Dementia Australia
Paul Sadler	Aged & Community Services Australia
Marlene Eggert	Leading Aged Services Australia Ltd
Prof. Sue Kurrle	Australia and New Zealand Society of Geriatric Medicine (ANZSGM) Cognitive Decline Partnership Centre
A/Prof. Meredith Blake	Cognitive Decline Partnership Centre (UWA)
Dr Craig Sinclair	Cognitive Decline Partnership Centre (UWA)
Sue Field	Cognitive Decline Partnership Centre (UWA)
Jennifer Thompson	Cognitive Decline Partnership Centre
Helen Connolly & Ivette Gonzalez	ACT Disability, Ageing and Carer Advocacy Service (ADACAS)
Conjoint Prof. Carmelle Peisah	UNSW, University of Sydney, Capacity Australia

Ingrid Ozols	Royal Australia & New Zealand College of Psychiatry (Consumer Co-Chair)
Dr Judith Silberberg	Royal Australian College of General Practitioners
Elizabeth Samra	ACT Law Society Elder Law & Succession Committee
Megan Corlis	Helping Hand Aged Care
Libby Simpson	Brightwater Group
Meredith Gresham	HammondCare
Melissa Clare	Commonwealth Bank Customer Advocacy Team
Les Stahl	Facilitation Plus Australia Pty Ltd

Appendix 2 – Program

Time	Topic	Speaker/s
09:00	Welcome to Country and Opening Session Welcome, Housekeeping, Overview of forum processes. Participant introductions	Wally Bell (Buru-Ngunawal) Forum Coordinator and Facilitator
09:30	Building Group Knowledge: Contexts & Resources Context: The National Plan on Elder Abuse [10 min] Context: A lived experience of Supported Decision-Making [10 min] Context: Supported decision-making for older people [15 min] Resources: Supported decision-making in the context of dementia [15 min] Resources: Review of supported decision-making resources relevant to situations of elder abuse [15 min] Questions and Facilitated Discussion [25 min]	[Commonwealth Attorney General Dept] Theresa Flavin John Chesterman (OPA Victoria) Craig Sinclair (CDPC) Ivette Gonzalez (ADACAS) Facilitator
11:00	Morning Tea Break	
11:20	Workshop 1: Identifying 3-5 key initiatives, partners and/or resources relevant to supported decision-making and pre-empting or responding to elder abuse Introduction / overview of workshop process – a facilitated process of ‘sequenced brainstorming’ Small group ideas generation (40 min) Rapid fire presentations of small group recommendations (20 min)	Small working groups with assigned facilitators (CDPC project team)
12:20	Workshop 2: Prioritising initiatives that will contribute to optimal implementation of supported decision-	

	making principles and practices in the National Plan on Elder Abuse Facilitated plenary discussion	Facilitator and all
13:00	Lunch Break	
14:00	Building Group Knowledge: Implementation issues at service provider level Presentations on challenges, solutions, resources required and how implementation could/should be structured Office of the Public Advocate South Australia – Anne Gale Elder Abuse Action Australia Network – Russell Westacott / Diedre Timms Aged Care Sector Peak Body Representative – Paul Sadler	Anne Gale (OPA South Australia) Russell Westacott / Diedre Timms Paul Sadler (ACSA)
14:40	Workshop 3: Agreeing on a set of high-level recommendations that can inform optimal implementation of supported decision-making principles and practices in the National Plan on Elder Abuse Facilitated plenary discussion	Facilitator and all
15:20	Afternoon Tea Break	
15:40	Workshop 4: Where to from here? Agreeing on ongoing collaborative work. Who needs to do what from here? Facilitated plenary discussion	Facilitator and all
16:20– 16:30	Closing Session	

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