Supported Decision-Making in Dementia Care: Final Project Report

Dr Craig Sinclair (University of Western Australia)
Prof. Susan Kurrle (University of Sydney)
Sue Field (University of Western Australia)
Assoc. Prof. Meera Agar (University of Technology Sydney)
Kathy Williams (Consumer Dementia Research Network)
Prof. Romola Bucks (University of Western Australia)
Prof. Josephine Clayton (University of Sydney, HammondCare)
Prof. Cameron Stewart (University of Sydney)
Assoc. Prof. Meredith Blake (University of Western Australia)
Assoc. Prof. Kirsten Auret (University of Western Australia)
Dr Meredith Gresham (HammondCare)
Dr Angelita Martini (Brightwater)
Helen Radoslovich (Helping Hand Aged Care)

COGNITIVE DECLINE PARTNERSHIP CENTRE
THE UNIVERSITY OF WESTERN AUSTRALIA
dementia australia
Brightwater
HammondCare
An independent Christian charity
Helping Hand

Full Project Title: Optimising advance care planning in dementia through supported decision-making: An exploratory mixed-methods study of community perceptions and law reform challenges in Australia (Cognitive Decline Partnership Centre 'Activity 24').

Suggested citation for this report: NHMRC Cognitive Decline Partnership Centre (CDPC). (2019). Supported Decision-Making in Dementia Care: Final Project Report. Sydney: NHMRC Cognitive Decline Partnership Centre. https://cdpc.sydney.edu.au

Contents

Executive Summary

Between March 2016 and June 2019 a multi-disciplinary investigator group were funded by the NHMRC Cognitive Decline Partnership Centre (CDPC) to investigate community attitudes and policy/law reform issues associated with supported decision-making in the context of dementia.

Key Research Findings

Through legal, policy and empirical social science research, the investigator team documented current practice in supported decision-making and areas where policy and practice will need to adapt. There was broad agreement with supported decision-making principles, and the moral and practical value of maintaining the involvement of the person with dementia in decision-making, for as long as possible. A range of resources were developed, to assist the community and the aged care and dementia care sectors to better understand and implement supported decision-making.

Key Research Outputs and Translational Outcomes

- 6 peer-reviewed journal articles/book chapters (published or in press);
- A supported decision-making Policy Guideline document for aged care providers, which has been cited as a guiding resource for the single aged care quality standards framework (June 2018);
- A suite of community-focused resources on supported decision-making (online and hard copy versions)[1];
- 11 conference/workshop presentations or clinical in-service presentations;
- 15 supported decision-making training workshops for aged care providers (in New South Wales and Western Australia);
- A set of consensus recommendations on the implementation of supported decision-making principles in the National Plan on elder abuse (October 2018);
- Intellectual Property agreements established to enable administering institution (UWA) to license third-party organisations to deliver supported decision-making training workshops (June 2019);
- Invitation to give written and oral evidence to the Royal Commission into Quality and Safety in Aged Care (June 2019).

[1] Note: online resources are available from https://cdpc.sydney.edu.au

Contributors

Investigators

Dr Craig Sinclair (Chief Investigator), Assoc. Prof. Meera Agar, Ms Sue Field, Prof. Susan Kurrle (CDPC Lead Investigators), Ms Kathy Williams (Dementia Australia Consumer Dementia Research Network Representative), Prof. Romola Bucks, Prof. Cameron Stewart, Assoc. Prof. Meredith Blake, Prof. Josephine Clayton, Assoc. Prof. Kirsten Auret (Investigators), Dr Meredith Gresham, Helen Radoslovich, Dr Angelita Martini, Rebecca Forbes, Pippa Cebis, Karla Seaman (CDPC Designated System Based Investigators)

Project Officers

Pia Castelli-Arnold, Dr Julie Bajic-Smith, Michelle Hogan, Kate Gersbach

Supported Decision-Making 'Interest Group' Members

New South Wales: Julie Bajic-Smith (Secretariat)[2], Craig Sinclair (Chair)[2], Justine O'Neill[3], Carolyn Smith[3], Theresa Flavin[4], Karine Shellshear[5], Darcelle Wu[4,6], Brendan Moore[7], Meredith Gresham[2], Cecilia Milani[8], Selen Akinci[8], Christine Mattey[9], Kerry Marshall[9], Pat Joyce[10], Melissa Chaperlin[10], Nalika Padmasena[10], Tom Hinton[11], Sally Lambourne[12], Kylie Miskovski[12], Kirsten Gibbs[12].

South Australia: Michelle Hogan (Secretariat)[2], Craig Sinclair (Chair)[2], Helen Radoslovich[2], Sue Lyons[13], Marie Farley[13], Yvette Gray[13], Anne Burgess[14], Anne Gale[15], Elly Nitschke[15], Shane D'Angelo[6], Ann Pietsch[4], Dr Margaret Brown[16], Dr Ron Sinclair[5], Dr Sue Jarrad[17], Rajiv Chand[12], Amy Orange[11], Rosa Colanero[8].

Western Australia: Kate Gersbach (Secretariat)[2], Craig Sinclair (Chair)[2], Dr Angelita Martini[2], Libby Thom[11], Wendy Bennett[18], Althea Gordon[19], Alana Fredericks[19], Cate McCullough[5], Mike Barry[4], Vicki Barry[5], Ursula Harbin[20].

The contributions of these individuals and organisations are gratefully acknowledged.

[2] Cognitive Decline Partnership Centre Investigator Team member
[3] NSW Office of the Public Guardian
[4] Consumer/Lived Experience Representative (person living with dementia)
[5] Consumer/Lived Experience Representative (current or former care partner)
[6] Aboriginal and Torres Strait Islander community member
[7] Leading Aged Services Australia
[8] Partners in Culturally Appropriate Aged Care (PICAC) Alliance member
[9] NSW Elder Abuse Helpline and Resource Unit
[10] Seniors Rights Service NSW
[11] Carers Australia representative
[12] Dementia Australia representative
[13] SA Department for Communities and Social Inclusion
[14] COTA representative
[15] SA Office of the Public Advocate
[16] University of South Australia
[17] Independent Consultant
[18] Advocare (WA)
[19] Alzheimers WA
[20] Australian Aged Care Quality Agency representative

Background

The Convention on the Rights of Persons with Disabilities (CRPD) establishes a right to "legal capacity on an equal basis with others in all aspects of life", and an obligation upon governments to provide citizens with access to support in their exercise of legal capacity (United Nations Enable, 2008). Implementation of the CRPD has proven challenging for systems in which substitute decision-making is the conventional response. Supported decision-making has been identified as an alternative to substitute decision-making, and a way of respecting a person's will and preference, while acknowledging the relational and inter-dependent nature of decision-making (Gooding, 2013).

The research to date in the area of supported decision-making has predominantly been in the form of policy analysis or descriptive evaluation of pilot programs (Bigby et al., 2017). There has also been relatively greater activity in supported decision-making among populations with intellectual disabilities and acquired brain injuries, as opposed to age-related cognitive impairments like dementia (Keeling, 2016). While there has been extensive legal and ethical commentary relating to supported decision-making, little is known about community attitudes towards supported decision-making, or the practical factors associated with its implementation (Carney & Beaupert, 2013; Kohn & Blumenthal, 2014).

The release of the Australian Law Reform Commission's (ALRC) report 'Equality, Capacity and Disability in Commonwealth Laws' (Australian Law Reform Commission, 2014) provides a framework for investigating community attitudes, and policy and law reform issues associated with supported decision-making within the Australian context. The National Decision-Making Principles are proposed to provide a blueprint for future reviews of Commonwealth legislation (including the Aged Care Act and the National Disability Insurance Scheme).

The ALRC National Decision-Making Principles are:

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

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;

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

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.

Research Objectives

Objective 1 – Legal and Policy Research

Examine relevant legislation, case-law, tribunal hearings and aged care provider organisational policies within three states (NSW, SA and WA) against the Australian Law Reform Commission's National Decision-Making Principles.

Objective 2 – Understanding Lived Experiences

Interview persons with dementia and their family members, supporters and care-partners, to better understand their lived experiences of healthcare and lifestyle decision-making, and perspectives on implementation of supported decision-making

Objective 3 – Professional Attitudes and Judgements

Interview and survey professionals in the healthcare and legal sectors, to understand their experiences facilitating decision-making in the context of dementia, and perspectives on implementation of supported decision-making

Objective 4 – Establish Supported Decision-Making Interest Groups

Facilitate an ongoing program of multi-disciplinary supported decision-making 'interest groups' in each of the three target states, to enable clinical translation and healthcare system change, while identifying opportunities for broader policy and legislative reform.

Objective 5 – Educational Resources

Develop materials and a pilot training program for 'support people', who might provide support for decision-making for people with dementia.

Project Milestones

This project was funded from March 2016 to 31 December 2018, within a quarterly milestone and reporting structure established within the Cognitive Decline Partnership Centre (CDPC). The following milestones were documented at the outset of the project, with milestones added following approval of additional funding during the project.

Timeframe	**Milestone**
2016 Quarter 1	Agreement on study protocol to enable submission for human research ethics (HREC) review
2016 Quarter 1	Submission of application for UWA HREC approval Study 1B (organisational policy analysis)
2016 Quarter 1	Recruitment of para-legal project officer
2016 Quarter 2	Submission of application for UWA HREC approval Study 2A and 2B (interviews with people with dementia and family members)
2016 Quarter 2	UWA HREC approvals Study 1B, 2A, 2B
2016 Quarter 2	Investigator team face to face meeting
2016 Quarter 3	Completed collation of relevant cases and tribunal hearings for Study 1A
2016 Quarter 3	Completed analysis of organisational policies and interviews with key informants (Study 1B)
2016 Quarter 4	Recruitment of project officers
2016 Quarter 4	Establishment of supported decision-making interest groups in WA, SA and NSW
2016 Quarter 4	Project officers to promote the goals of the project in each organisation and support recruitment (Study 2A, 2B)
2017 Quarter 1	Submission of application for UWA HREC approval for Study 3A (interviews with professionals)
2017 Quarter 1	Project officers are endorsed by their organisations to initiate relevant practice improvement activities, that facilitate evidence-based principles of supported decision-making
2017 Quarter 2	Website development for online factorial survey
2017 Quarter 2	Completion of interviews for Study 2A
2017 Quarter 2	First meeting of supported decision-making interest groups in WA, SA and NSW (focused on preliminary data analysis and practical implementation at organisational level
2017 Quarter 2	Submission of manuscript(s) detailing Study 1 findings to peer-reviewed journal
2017 Quarter 2	Provision of policy analysis feedback to participating organisations in Study 1B
2017 Quarter 3	Completion of interviews for Study 2B
2017 Quarter 4	Second meeting of supported decision-making interest groups in WA, SA and NSW (focused on preliminary data analysis, practical implications at organisational level and vignette generation for Study 3B)

2017 Quarter 4	Submission of manuscript(s) detailing Study 2 findings to peer-reviewed journal
2017 Quarter 4	Submission of application for UWA HREC approval for Study 3B
2018 Quarter 1	Completion of consultation to inform the development of educational resources
2018 Quarter 2	Third meeting of supported decision-making interest groups in WA, SA and NSW (focused on preliminary data analysis and practical implications at organisational level)
2018 Quarter 2	Establishing strategy for implementing webinars
2018 Quarter 3	Completion of educational resources
2018 Quarter 3	Submission of manuscript(s) detailing Study 3 findings to peer-reviewed journal
2018 Quarter 4	Delivery of a forum on decision-making and cognitive decline, involving academic, consumer, industry, policy and government
2019 Quarter 2	Preparation of final project report and endorsement by relevant stakeholders
2019 Quarter 2	Submission of final project report to CDPC
2019 Quarter 2	Completion of program of workshops for aged care providers on supported decision-making, with evaluation of acceptability and feasibility

Supported Decision-Making Interest Groups

In keeping with the emphasis of Cognitive Decline Partnership Centre Research Activities on research that informs evidence-based changes in policy and practice, a supported decision-making 'interest group' was established in each of the target states. The focus for these interest groups was to:

- Collaborate with the research team in framing research questions and interpret data
- Identify opportunities for clinical translation, healthcare system changes and policy/law reform, and advise on optimal avenues for research translation and policy advocacy
- Assist in the dissemination of research findings and outputs among professional and community networks, to facilitate greater understanding and adoption of supported decision-making principles.

Interest group membership was established during late 2016, with the initial meeting in each state convened in early 2017. The groups met approximately quarterly until mid-2018, with each group meeting five times. Meetings were 2-3 hours in duration with minutes taken by the investigator team (secretariat or chair). Project grant funding was used to cover appropriate expenses for interest group members, subject to an agreed 'terms of reference' document, which was established as part of the first meeting. This included payment of sitting fees for consumer/lived experience representatives. Consumer/lived experience representatives were also eligible for involvement in dissemination activities.

NSW Supported Decision-Making interest group (2017).

Summary of Research Findings

Analysis of legislation, case law, and tribunal hearings

This component of the project commenced early and continued throughout the project, culminating in ten submissions to government relating to reviews of legislation and proposals for law reform. The research used the ALRC National Decision-Making Principles as a guiding framework, and undertook analysis across the three states (e.g. Guardianship and Mental Health Act legislation), with additional consideration of relevant pieces of Commonwealth legislation. Analysis of case law and tribunal hearings involving matters relating to healthcare and lifestyle decision-making among people with dementia narrowed the focus to issues within the Guardianship legislation in each of the three states, as well as the relevant Tribunal processes that might influence involvement in decision-making by persons with dementia. Of particular relevance was consideration of statutory and common law definitions of 'decision-making capacity', the principles underpinning substitute decision-making, and the legal pre-conditions necessary for the appointment of a Guardian.

The analysis found that there was very little reference to supported decision-making terminology or principles in any of the three pieces of Guardianship legislation. In New South Wales (NSW) and Western Australia (WA) a 'best interests' standard is applied for substitute decision-making, while in South Australia (SA) a 'substituted judgement' standard is applied. The substituted judgement standard is considered to be more consistent with a human rights-based approach, and more respectful of the autonomy of a person who comes under Guardianship orders. One hundred and thirteen relevant tribunal hearings were analysed from across the three jurisdictions, to better understand how these different pieces of legislation were interpreted in practice, in the context of decision-making among people living with dementia.

Policies of aged care organisations

During 2016, approved Australian aged care providers were invited to participate in a project examining organisational policies relating to healthcare and lifestyle decision-making. Participating organisations submitted their existing policies and procedures in the area of healthcare and lifestyle decision-making, for confidential review by a sub-group of

the investigator team and provision of confidential, tailored feedback. De-identified, aggregated results were collated for publication. Key staff with policy roles within each organisation were also interviewed, to better understand the factors influencing implementation of policies consistent with supported decision-making principles. Organisational policies were analysed with reference to the Australian Law Reform Commission National Decision-Making Principles (Australian Law Reform Commission, 2014), with the following key findings:

- With respect to Principle 1 (an equal right to make decisions), none of the participating organisations met all of the audit domains relating to best practice (i.e. functional/rights-based approach to assessment of decision-making capacity);
- Only three out of seven organisations had a specific policy relating to the assessment of decision-making capacity;
- All organisations referred to prevailing (state) legislation relating to substitute decision-making;
- With respect to Principle 2 (the right to support in making decisions), while most policies acknowledged care recipients' rights and the importance of providing support, there was little clarification for staff as to what this involved;
- With respect to Principle 3 (will, preferences and rights directs decision-making), none of the policies made explicit reference to contemporary concepts such as 'will, preference and rights' in decision-making;
- Interviews with key staff in policy development roles indicated agreement with the principles of supported decision-making, but noted a number of implementation challenges, including the complex policy and regulatory landscape, intra-organisational challenges in implementing policies, resource limitations and an overall risk-averse and compliance-focused sector.

These findings are currently being published (Sinclair, Field, Blake, & Radoslovich, in press), and evidence-based guidelines include a Policy Guideline document for aged care providers (Sinclair, Blake, & Field, 2018).

Interviews with people living with dementia and their family members

Through interviews with people living with dementia and their family members, the investigator team heard how decision-making is conceptualised as a relational and inter-personal process, which unfolds over time, often in response to stressful external triggers. Interview participants endorsed the moral and practical value of 'maintaining involvement' in decision-making, and both people with dementia and their family members acknowledged that progressive cognitive impairment would likely require greater involvement of others in decision-making over time (Sinclair, Gersbach, et al., in press; Sinclair, Gersbach, et al., 2018).

A range of strategies were reported as being already employed by family members and supporters, to maintain involvement of people with dementia in decision-making. These included:

- Allowing extra time;
- Identifying optimal situations for decision-making (e.g. time of day, environment);
- Repeating and reinforcing information;
- Communicating through multiple sensory modalities (e.g. auditory, visual);
- Employing prompts and communication aids;
- Translating jargon and simplifying abstract concepts;
- Presenting a reduced number of options;
- Breaking decisions down into stages and dealing with one topic at a time;
- Knowing the person well and understanding their wishes;
- Keeping other family members involved and communicating transparently;
- Managing (but not removing) risks.

Our investigator team has proposed a 'spectrum model' of supported decision-making, to inform policy and practice. This approach recognises that a range of different levels and types of support will be required across a person's journey with dementia. Such an approach has scope for 'supporters' and (as a last resort) 'representatives', whose job would be to ensure that the person's will, preferences and rights direct decisions about their lives. The investigator team has made further recommendations about the implementation of such a 'spectrum model' in dementia care, which includes a number of key aspects:

- A formal framework for supported decision-making, which includes scope for 'supporters' and 'representatives';
- Development of a professional supported decision-making facilitator role;
- Advocacy, education and community development to develop service provider knowledge and skills and address social and contextual barriers.

The research findings are translated into a number of practical resources aimed at raising community and professional awareness and promoting the implementation of supported decision-making principles.

Interviews with professionals involved in dementia care

Through interviews with professionals involved in dementia care, the investigators examined current practice in the area of supported decision-making. Twenty-eight health (medical, nursing, allied health) and legal professionals participated in interviews, which focused on practices associated with capacity assessment, assistance in decision-making and the involvement of family members or other supporters in decision-making processes. Participants were generally in favour of the idea of providing support and assistance in decision-making for people with dementia, although they varied in terms of their skills, strategies and approach to this. Key themes emerging from this research included '**Establishing a basis for decision-making**', '**The supportive toolbox**', and **'Managing professional boundaries**'. Taking a holistic approach to capacity assessment, knowing the person and their support networks well, engaging generic or specialised supportive techniques (within the professional's own skill set) and being attentive to non-verbal cues were considered to be relevant in supporting a person's decision-making. Professionals also noted the need to acknowledge their own scope of practice and maintain professional distance in decision-making.

Through analysis of these interviews the investigators identified a continuum of practice, ranging from an 'individualist advocacy' approach through to a 'relational practice' approach. Those aligning with the 'individualist advocacy' approach tended to adopt a 'black and white' conceptualisation of decision-making capacity, and were strict in terms of

identifying the individual as their client, often denying involvement of family members or other supporters. This was often explained with reference to promoting or protecting the rights of the individual. Those aligning with the 'relational practice' approach tended to welcome the involvement of family members or other supporters across all stages of the cognitive impairment, with an understanding that there would be increasing reliance on family members or supporters over time. This approach emphasised 'involvement' of the person with dementia, although it was sometimes unclear the extent to which the person's 'will and preference' was central to the decision-making. Both of these approaches have potential utility in some scenarios, but can also be seen to be inconsistent with supported decision-making principles, particularly at the extreme ends of the continuum.

This research is currently in the process of publication (Sinclair, Bajic-Smith, et al., in press) and has informed the development of supported decision-making training materials for professionals and aged care providers, as well as a program of webinar recordings targeted to this audience.

Vignette survey of health professionals and aged care workers

This study aimed to extend the previous qualitative study of health professionals, to test hypotheses and better understand the key factors influencing the involvement of people with dementia in healthcare and lifestyle decision-making. The investigators developed a bank of hypothetical vignettes of plausible clinical and care transition decision-making scenarios. The vignettes manipulated the person's age, person's gender, supporter relationship, supporter availability, cognitive impairment severity, decision type and decision urgency. For each vignette, survey participants were asked to rate whether the person could be involved in the decision, or make the decision independently. Participants also completed demographic information and a survey on their attitudes towards people living with dementia, to determine whether these variables had an effect. Multi-level regression models were used to determine the relative influence of the different factors.

Complete responses were received from 140 participants. For judgements about whether the person with dementia could be involved in the decision, participants were more likely to judge 'YES' for decisions:

- involving residential care admission (compared to medical treatment decisions);
- when the person had 'mild' or 'moderate' cognitive impairment (compared to 'severe');
- Aged care workers were less likely to judge 'YES' across all vignettes.

For judgements about whether the person could make the decision independently, participants were more likely to judge 'YES':

- when the person with dementia was male (compared to female);
- younger (70 years compared to 90 years);
- had 'mild' cognitive impairment (compared to 'moderate' or 'severe'); and
- if the professional themselves had more years of experience.

This research has indicated that professional judgements about decision-making among people with dementia are influenced by person, context and professional characteristics. The effects of the age and gender of the person with dementia on the professionals' judgements may reflect the operation of unconscious bias.

The program of doctrinal and empirical research described in this section has provided an evidence-base for the suite of practical resources and translational research activities that are described below.

Supported Decision-Making Resources

During 2018, the focus of the project shifted from collecting and analysing data, to disseminating findings and developing practical resources for practitioners and the community. A key issue was the current lack of awareness relating to supported decision-making, and the need for resources to clarify terminology and provide 'first steps' in implementing practical support for decision-making. Another issue was the lack of a legal framework for supported decision-making in most Australian states. Hence resources were necessarily focused on clear definitions, describing good practice and pointing to areas for future policy and law reform. With respect to the Aged Care Act however, it was possible to provide some more specific guidance for aged care providers regarding the intersection between the ALRC National Decision-Making Principles and the incoming single Aged Care Quality Standards framework. The resources are described below.

Policy Guidelines Document

This policy guideline document is targeted at Australian aged care providers, and provides information to assist providers in understanding supported decision-making, assess their own policies, identify alignment between existing policies and incoming aged care standards, promote interactive discussion with staff, and begin the process of policy reform. The policy guideline was launched in Sydney in June 2018, with presentations from Dr Craig Sinclair, Theresa Flavin (lived experience representative) and Professor Susan Kurrle.

Since the launch of the document, more than 950 copies of the resource have been distributed to a range of key stakeholders across Australia. The policy guideline has been cited by the Aged Care Quality and Safety Commission, as a resource for aged care providers to use in demonstrating their compliance with incoming aged care standards (particularly Standard 1 'Consumer Dignity and Choice' and Standard 2 'Ongoing Assessment and Planning with Consumers). The NSW Public Guardian's office has provided a direct link to this document from their website section "What is Supported Decision-Making (SDM)".

Launch of the 'Supported Decision-Making in Aged Care' Policy Development Guideline

Training Package

An introductory training package was developed during 2018, with input from all project stakeholders (particularly partnering aged care organisations). The package was designed as 4-6 hour interactive group session, with a heavy emphasis on participants' existing skills and experiences, case-based discussion and adult learning principles. The package draws on the existing suite of supported decision-making resources, and is also accompanied by presenter materials (powerpoint slides and guidelines for group activities) and a participant workbook. The training package was piloted during August-October 2018, with six sessions undertaken

across NSW and WA. Two additional 'train-the-trainer' sessions piloted an approach to equipping staff champions to implement the training materials more broadly across their organisations. During 2019 remaining project funds were utilised to expand the training package (additional 11 sessions), running further sessions with aged care providers across NSW (in partnership with the NSW Public Guardian) and evaluating the package more formally.

Pilot supported decision-making training package session

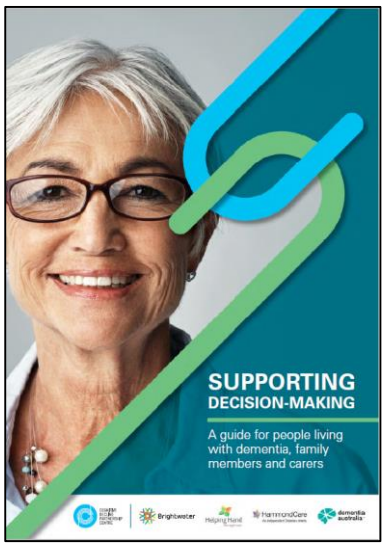
Webinar Series

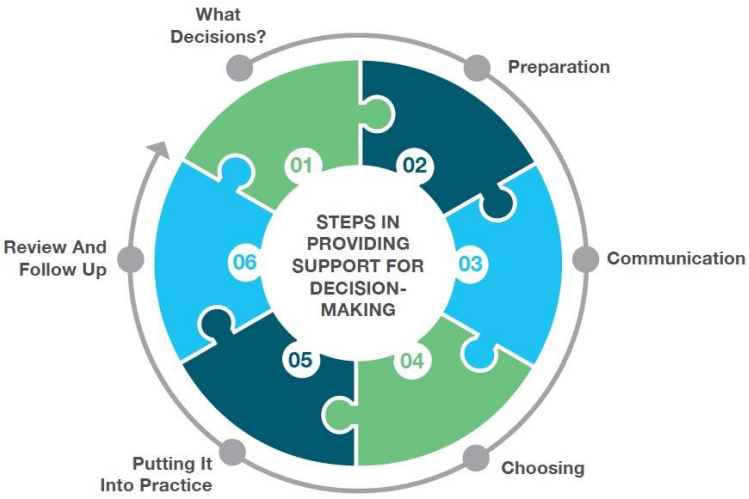
Parallel to the training sessions piloted during 2018, the investigator group recorded a series of three, 60-minute webinars. These webinar sessions discussed different areas of supported decision-making, communicated the research findings and provided a shortened version of the training materials to aged care provider organisations and other interested participants from around Australia. The three webinar sessions achieved moderate registration and attendance rates (Webinar 1: 105 registrants, 37 live participants; Webinar 2: 133 registrants, 46 live participants; Webinar 3: 100 registrants, 24 live participants). The

webinars included a person with lived experience of dementia and a care-partner of a person with dementia, as well as members of the investigator group.

Consumer Guidebook and Helpsheets

A key outcome from the project was to develop supported decision-making resources for the community, including people living with dementia, their family members and potential supporters. A guidebook resource was developed by the investigator group, which drew upon the research interviews and had extensive feedback from members of the Supported Decision-Making Interest Groups, including consumer/lived experience representatives. A shorter, 2-page 'helpsheet' was also developed, and translated into Greek, Italian and Mandarin.





Supported decision-making consumer guidebook and 'decision-making steps'

Over 1000 copies of the consumer guidebook have been distributed by CDPC team members to key stakeholder organisations (e.g. older person's rights groups, Dementia Australia, partner aged care provider organisations, Carers Australia branches) during 2018 and 2019.

Translation into Policy and Practice

Training Workshops for Aged Care Providers

During 2018, the investigator group developed materials for a half-day training package, covering the human rights principles underpinning supported decision-making, lived experiences of people living with dementia and their family members regarding supported decision-making, a series of case-based exercises to promote a problem-solving approach to providing supported decision-making, and links to further resources. The training package was piloted in six sessions with aged care providers in WA and NSW and refined in response to feedback. During the first half of 2019, the training package was delivered more broadly across NSW (11 sessions) in partnership with the NSW Office of the Public Guardian, and more formally evaluated. Of the 152 participants who responded to the evaluation (96% response rate):

- 96% agreed or strongly agreed that the training was relevant to their role;
- 97% agreed or strongly agreed that the training had increased their awareness of supported decision-making principles;
- 97% agreed or strongly agreed that the training had increased their understanding of the strategies for supporting decision-making among clients in aged care settings;
- 100% agreed or strongly agreed that they were likely to apply the material learned in their practice.

The investigator team have prepared legal documentation to enable third-party organisations to enter into License Agreements with the administering institution (University of Western Australia) to use the training materials within their own organisations.

Care partner support group

During 2018, Helping Hand Aged Care (SA) convened four facilitated group sessions, involving six people who identified as care-partners of people living with dementia. The aims of the group were to:

1. learn about and contribute to the Cognitive Decline Partnership Centre Supported Decision-Making in Dementia Care project;

2. meet other people who also support someone living with dementia, share stories and experiences
3. generate learnings about the issues faced by care-partners of people living with dementia in implementing supported decision-making

The sessions were structured around some learning input (provided by facilitators and using existing project resources), and on-going sharing of experiences as the members practiced the supported decision-making techniques described in the consumer guide.

Learnings from the care-partner support group included:

1. Care-partners with different experiences all found value in discussing the consumer guidebook and learning about supported decision-making. This included those caring for someone with a recent diagnosis or emerging symptoms of dementia as well as long-term carers.
2. Carers were able to reflect on their own behaviour around decision making e.g. talking to others about decisions rather than including the person living with dementia in the discussion;
3. The group process was a valuable way for carers to learn about decision-making, with the mix of different experiences contributing to learning exchange;
4. One longer-term carer believed he had a lot to contribute in sharing his experiences and supporting newer carers;
5. The participants found it very easy to relate to the concept of supported decision making. The discussion and sharing was a useful technique for getting ideas on how to put it into practice.

This group did not continue after the research project concluded, partly due to resource constraints and partly as the members felt that they had learnt as much as they needed at that point in time.

Incoming single aged care standards framework

The Supported Decision-Making Policy Guideline for Aged Care Providers document has been cited by the Aged Care Quality and Safety Commission as a resource relevant to

meeting the requirements of the incoming single aged care standards framework (Standard 1: Consumer Dignity and Choice; Standard 2: Ongoing Assessment and Planning with Consumers). Australian aged care providers are accredited against these incoming standards from 1st July 2019.

Government submissions

New South Wales Law Reform Commission

The investigator group contributed five submissions to the New South Wales Law Reform Commission, in relation to the Inquiry into the *Guardianship Act 1987* (NSW). These submissions included references to work undertaken in the project, including evidence collected from analysis of legislation and interviews with people living with dementia and their family members and supporters. This included a number of opportunities to meet with the Commission staff and discuss the ongoing work. The New South Wales Law Reform Commission released its final report in late 2018, which included recommendations for formal legal recognition of supported decision-making arrangements (New South Wales Law Reform Commission, 2018). The response of the NSW Government is currently pending.

Western Australian Joint Select Committee into End of Life Choices

Three of the investigators (Dr Craig Sinclair, Assoc. Prof. Kirsten Auret and Assoc. Prof. Meredith Blake) made submissions to the WA Joint Select Committee into End of Life Choices. All three appeared before the Committee as part of the inquiry proceedings, and Assoc. Prof. Auret was later invited to participate in the Expert Advisory Panel, responsible for advising on the drafting of legislation in response to the Committee's findings and recommendations.

Australian Guardianship Association Council guidelines on maximising participation of the person in guardianship proceedings

Dr Craig Sinclair and Sue Field made a submission in response to the draft Australian Guardianship Association Council's guidelines on maximising participation of the person in guardianship proceedings. This submission included consideration of supported decision-

making principles in the context of guardianship proceedings, to better enable the person to take an active role in the process.

Royal Commission into Quality and Safety in Aged Care

In May 2019 Dr Craig Sinclair was invited to provide a written statement to the Royal Commission into Quality and Safety in Aged Care. In June 2019 Dr Sinclair appeared before the Commission to give evidence, and was able to present findings from the supported decision-making project, as well as promote the adoption of the ALRC National Decision-Making Principles as part of the Commission's recommendations.

Forum on supported decision-making in the National Plan on elder abuse

During October 2018, the investigator group convened a facilitated forum in Canberra, aimed at generating consensus recommendations on the implementation of supported decision-making in the National Plan on elder abuse. This forum included a diverse range of consumer representatives, key advocacy organisations (e.g. Culturally and Linguistically Diverse (CaLD) community service providers, aged care peak bodies, clinician Colleges), government department representatives and members of the research team.

The consensus recommendations from the forum were:

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.**

Consensus forum on supported decision-making in the National Plan on elder abuse (October 2018).

The report on this forum, and consensus recommendations was submitted to the Council of Attorneys-General Working Group on Protecting the Rights of Older Australians, and made publically available on the Cognitive Decline Partnership Centre website (Sinclair & Stahl, 2018).

Future Directions

The NHMRC Cognitive Decline Partnership Centre (CDPC) 'Supported Decision-Making in Dementia Care' project developed a suite of resources and mobilised networks to support ongoing implementation. It is important that ongoing work is undertaken to further disseminate these resources and to continue to work towards implementation of the key recommendations arising from the research. A number of future directions for research and implementation have been identified:

- A trial of supported decision-making implementation within a specific organisation (e.g. aged care or dementia care provider organisation) would fill a critical gap in the research, relating to empirical evidence on the benefits and/or adverse events that might result from this approach. Such research should continue to actively involve people living with dementia and those with experience as care-partners of people with dementia.
- Enable third party organisations to enter into License Agreements, allowing them to use the supported decision-making training package within their own organisation.
- Feedback from training workshops suggested the need for additional training material (including multimedia resources), which are specifically targeted to the needs of those working in the residential aged care context, including in the situation of caring for people with more advanced cognitive and/or functional impairments.
- To undertake broader consultation with diverse community groups (e.g. Aboriginal and Torres Strait Islander and CaLD communities and culturally-specific service provider organisations), to better understand the areas in which the existing supported decision-making resources may be useable, and where they may require adaptation.
- To ensure that the project resources and materials continue to be made available, including beyond the completion of funding for this project and the Cognitive Decline Partnership Centre.
- To continue to advocate for the inclusion of supported decision-making training as a core part of the curriculum for staff entering the aged-care and disability-care sectors.
- To continue to advocate for the adoption of the National Decision-Making Principles, as a way of promoting a nationally consistent approach to supported decision-making in legislation and policy.

Acknowledgements

The investigator team would like to acknowledge the contributions of interest group members, partner organisations, research participants and their supporters. The authors acknowledge the contribution of Funding Bodies (National Health & Medical Research Council) and Funding Partners (Dementia Australia, HammondCare, Helping Hand Aged Care, Brightwater Group). The contents of the above report and materials are solely the responsibility of the individual authors identified, and do not reflect the views of the Funding Bodies or the Funding Partners.

References

Australian Law Reform Commission. (2014). *Equality, Capacity and Disability in Commonwealth Laws*. Retrieved from Sydney: https://www.alrc.gov.au/publications/equality-capacity-disability-report-124

Bigby, C., Douglas, J., Carney, T., Then, S. N., Wiesel, I., & Smith, E. (2017). Delivering decision making support to people with cognitive disability — What has been learned from pilot programs in Australia from 2010 to 2015. *Australian Journal of Social Issues, 52*(3), 222-240. doi:10.1002/ajs4.19

Carney, T., & Beaupert, F. (2013). Public and private bricolage: Challenges balancing law, services and civil society in advancing CRPD supported decision-making. *University of New South Wales Law Journal, 36*(1), 175-201. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=lft&AN=88867034&site=ehost-live

Gooding, P. (2013). Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law. *Psychiatry Psychology and Law, 20*(3), 431-451. doi:10.1080/13218719.2012.711683

Keeling, A. (2016). Supported decision making: the rights of people with dementia. *Nursing Standard, 30*(30), 38-44.

Kohn, N. A., & Blumenthal, J. A. (2014). A critical assessment of supported decision-making for persons aging with intellectual disabilities. *Disability and Health Journal, 7*, S40-S43. doi:10.1016/j.dhjo.2013.03.005

New South Wales Law Reform Commission. (2018). *Review of the Guardianship Act 1987: Report 145*. Retrieved from Sydney:

Sinclair, C., Bajic-Smith, J., Blake, M., Clayton, J. M., Bucks, R. S., Field, S., . . . Kurrle, S. (in press). Professionals' views and experiences in supporting decision-making involvement for people living with dementia. *Dementia*.

Sinclair, C., Blake, M., & Field, S. (2018). Supported decision-making in aged care: A policy development guideline for aged care providers in Australia. Retrieved from http://sydney.edu.au/medicine/cdpc/documents/resources/SDM-Policy-Guidelines.pdf

Sinclair, C., Field, S., Blake, M., & Radoslovich, H. (in press). An examination of organisational policies for healthcare and lifestyle decision-making among Australian aged care providers. *Australasian Journal on Ageing*.

Sinclair, C., Gersbach, K., Hogan, M., Blake, M., Bucks, R. S., Auret, K. A., . . . Kurrle, S. (in press). “A real bucket of worms”: Views of people living with dementia and family members on supported decision-making. *Journal of Bioethical Inquiry*.

Sinclair, C., Gersbach, K., Hogan, M., Bucks, R. S., Auret, K. A., Clayton, J. M., . . . Kurrle, S. (2018). How couples with dementia experience healthcare, lifestyle, and everyday decision-making. *International Psychogeriatrics*, 1-9. doi:10.1017/S1041610218000741

Sinclair, C., & Stahl, L. (2018). *Supported decision-making in the National Plan on Elder Abuse: Consensus Recommendations*. Retrieved from Sydney: http://sydney.edu.au/medicine/cdpc/documents/resources/SDM-elder-abuse-forum-FINAL-REPORT.pdf

United Nations Enable. (2008). Convention on the Rights of Persons with Disabilities, Article 12. Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Appendix 1: Summary of Research Outputs

Peer-reviewed publications

Sinclair, C., Bucks, R., Williams, K., Blake, M., Field, S., Clayton, J., Callaghan, S., Radoslovich, H., Auret, K., Kurrle, S. (2018). "We've always thought of one another": Relational perspectives on autonomy and decision-making among people with dementia and their family carers. In McDonald, G., Mears, J. (Eds). ***Dementia as Social Experience: Valuing Life and Care.*** Oxford: Routledge.

Sinclair, C., Gersbach, K., Hogan, M., Bucks, R., Auret, K., Clayton, J., Agar, M., Kurrle, S. (2018). How couples with dementia experience healthcare, lifestyle and everyday decision-making. ***International Psychogeriatrics***. 1-9 DOI: 10.1017/S1041610218000741.

Sinclair, C., Field, S., Blake, M., Radoslovich, H. (in press). An examination of organisational policies for decision-making, consent and capacity assessment among Australian aged care providers. ***Australasian Journal on Ageing***.

Flavin, T., Sinclair, C. (in press). Reflections on involving people living with dementia in research in the Australian context. ***Australasian Journal on Ageing***. (invited commentary).

Sinclair, C., Bajic-Smith, J., Blake, M., Clayton, J., Bucks, R., Field, S., Radoslovich, H., Gresham, M., Agar, M., Kurrle, S. (in press). Professionals' views and experiences in supporting decision-making involvement for people living with dementia. ***Dementia***.

Sinclair, C., Gersbach, K., Hogan, M., Blake, M., Bucks, R., Auret, K., Clayton, J., Stewart, C., Field, S., Radoslovich, H., Agar, M., Martini, A., Gresham, M., Williams, K., Kurrle, S. (in press). "A real bucket of worms": Views of people living with dementia and family members on supported decision-making. ***Journal of Bioethical Inquiry***.

Technical Reports, White Papers or Policy Directives

Sinclair, C., Agar, M., Field, S., Kurrle, S., Williams, K., Bucks, R., Clayton, J., Stewart, C., Blake, M., Auret, K., Callaghan, S., Radoslovich, H. (2016). **Submission in response to consultation on Version 2 of the National Safety & Quality in Health Care Standards**. Submitted 5/8/2016.

Sinclair, C., Castelli-Arnold, P., Blake, M., Williams, K., Stewart, C., Agar, M., Field, S. (2016). **Submission to the NSW Law Reform Commission Inquiry into the Guardianship Act 1987 – Question Paper 1: Preconditions for Guardianship**. Submitted 18/10/2016. http://www.lawreform.justice.nsw.gov.au/Documents/Current-projects/Guardianship/Submissions/GA14.pdf

Field, S., Sinclair, C., Bucks, R., Stewart, C., Blake, M., Williams, K., Callaghan, S., Auret, K., Agar, M. (2017). **Submission to the NSW Law Reform Commission Inquiry into the Guardianship Act 1987 – Question Paper 2: Models of supported decision-making**. Submitted 3/2/2017. http://www.lawreform.justice.nsw.gov.au/Documents/Current-projects/Guardianship/Submissions/GA63.pdf

Field, S., Stewart, C., Sinclair, C., Bucks, R. (2017). **Submission to the NSW Law Reform Commission Inquiry into the Guardianship Act 1987 – Question Paper 4**. Submitted

22/5/2017. http://www.lawreform.justice.nsw.gov.au/Documents/Current-projects/Guardianship/Submissions/GA112.pdf

Field, S., Stewart, C., Sinclair, C., Bucks, R. (2017). **Submission to the NSW Law Reform Commission Inquiry into the Guardianship Act 1987 - Question Paper 5**. Submitted 22/5/2017. http://www.lawreform.justice.nsw.gov.au/Documents/Current-projects/Guardianship/Submissions/GA112.pdf

Blake, M., Sinclair, C. (2017). **Submission to the WA Joint Select Committee on End of Life Choices**. Submitted 23/10/2017. http://www.parliament.wa.gov.au/Parliament/commit.nsf/a7b778ee55fef62a4825772700174a2c/fae07f96a48fe14a4825821e000fc6cd?OpenDocument

Sinclair, C., Williams, K., Kurrle, S. (2018). **Submission to the NSW Law Reform Commission Inquiry into the Guardianship Act 1987 – Draft Proposal**. Submitted 10/2/2018. http://www.lawreform.justice.nsw.gov.au/Documents/Current-projects/Guardianship/Submissions/GA156.pdf

Sinclair, C., Field, S., Blake, M. (2018). ***Supported Decision-Making in Aged Care: A Policy Development Guideline for Aged Care Providers in Australia***. Sydney: Cognitive Decline Partnership Centre. http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php

Sinclair, C., Stahl, L. (2018). ***Supported decision-making in the National Plan on elder abuse: Consensus Recommendations***. Sydney: Cognitive Decline Partnership Centre. http://sydney.edu.au/medicine/cdpc/documents/resources/SDM-elder-abuse-forum-FINAL-REPORT.pdf

Sinclair, C., Blake, M. (2018). **Submission to the Working Group on Protecting the Rights of Older Australians regarding the Draft National Plan on Elder Abuse**. Submitted 31/7/2018.

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

Sinclair, C., Field, S. (2019). **Submission to the Australian Guardianship Association re: Draft Guidelines on maximising the participation of the person in guardianship proceedings**. Submitted 14/1/2019.

Sinclair, C. (2019). **Submission to the Royal Commission into Quality and Safety in Aged Care**. Submitted 28/5/2019.

Meeting presentations / Workshops

Blake, M., Sinclair, C. (2016). Advance care planning and dementia: Reflections on a Western Australian study. Oral presentation at the **2016 Conference of the Adult Guardianship and Administration Council (AGAC)**, Sydney, NSW.

Sinclair, C., Bucks, R., Williams, K., Blake, M., Field, S., Clayton, J., Callaghan, S., Radoslovich, H., Auret, K., Kurrle, S. (2017). Experiences of decision-making and advance care planning by people with dementia. Oral presentation at the **2017 Reframing Dementia Workshop**, Sydney, NSW.

Sinclair, C., Gersbach, K., Hogan, M., Bucks, R., Blake, M., Auret, K., Williams, K., Clayton, J., Radoslovich, H., Callaghan, S., Field, S., Agar, M., Stewart, C., Gresham, M., Martini, A., Bajic-Smith, J., Kurrle, S. (2017). Substitute or Supported Decision-Making? Learning from the lived experiences of people with dementia and their carers to guide practice, policy and law reform. Poster presentation at the **2017 NNIDR Australian Dementia Forum**, Melbourne, Victoria.

Blake, M., Castelli-Arnold, P., Field, S., Stewart, C., Callaghan, S., Sinclair, C. (2017). Supported decision-making and dementia: Observations from legislation and case law in three Australian states. Poster presentation at the **2017 NNIDR Australian Dementia Forum**, Melbourne, Victoria.

Bajic-Smith, J., Sinclair, C. (2017). Understanding the factors influencing health professionals' use of Supported Decision-Making in the context of dementia. Poster presentation at the **2017 NNIDR Australian Dementia Forum**, Melbourne, Victoria.

Sinclair, C., Gersbach, K., Hogan, M., Bucks, R., Blake, M., Williams, K., Clayton, J., Auret, K., Radoslovich, H., Callaghan, S., Field, S., Agar, M., Stewart, C., Gresham, M., Martini, A., Bajic-Smith, J., Kurrle, S. (2017). Substitute or supported decision-making? Learning from the lived experiences of people with dementia and their carers to guide practice, policy and law reform. Oral presentation at the **2017 Alzheimer's Australia Biennial National Conference** , Melbourne, Victoria.

Blake, M. (2018). "A real bucket of worms": Supported decision-making and dementia in Australia: Reflections on the law and lived experiences. Oral presentation at the **2018 International Dementia Conference: Growing Excellence in Dementia Care**, Dublin, Ireland.

Sinclair, C., Field, S., Blake, M., Bucks, R., Agar, M., Clayton, J., Auret, K., Stewart, C., Williams, K., Radoslovich, H., Gresham, M., Martini, A., Kurrle, S. (2018). Supported decision-making in the context of dementia: Collaboration at the coalface of human rights and decision-making. Oral presentation at **2018 NNIDR Australian Dementia Forum**, Sydney, NSW.

Flavin, T., Sinclair, C. (2018). Supported decision-making: The lived experience of consumer impact in dementia research. Oral presentation at **2018 NNIDR Australian Dementia Forum**, Sydney, NSW.

Sinclair, C., Flavin, T., Sinclair, R., Kurrle, S. (2018). Supported decision-making in the age of choice: How is this going to work for people with dementia? Panel presentation at **2018 HammondCare International Dementia Conference**, Sydney, NSW.

Sinclair, C., Field, S. (2018). Supported decision-making for aged care providers. Invited presentation to **NSW Public Guardian 'Supported Decision-Making Community of Practice'**. Sydney, NSW.

Sinclair, C. (2019). Maximising the participation of people with decision-making disabilities in guardianship proceedings: Illusory or achievable? Invited panel presentation at the **2019 Australian Guardianship Association Conference**, Canberra, ACT.

Sinclair, C. (2019). Supported decision-making. Invited presentation and panel attendance at the **2019 NNIDR Lecture Tour Roadshow**, Sydney, NSW.

Sinclair, C. (2019). Supported decision-making. Invited presentation at **Dementia Australia Client Services Staff Training Day**, Sydney, NSW.

Sinclair, C. (2019). Health professional judgements regarding decision-making involvement among people living with dementia. Poster presentation at **2019 NNIDR Australian Dementia Forum**, Hobart, Tasmania.

Industry Articles

Belardi L, Egan N. (2017). New guidance for providers on supported decision-making. ***Australian Ageing Agenda***. Accessed 2/11/2017 from https://australianageingagenda.com.au/2017/11/01/new-guidance-providers-supported-decision-making/

Morton H. (2017). Substitute or supported decision-making. ***Cognitive Decline Partnership Centre newsletter***. Published online 22/11/2017 http://sydney.edu.au/medicine/cdpc/news-events-participation/decision-mkg.php

Australian Aged Care Quality Agency (2018). Survey and guidelines: Dementia and decision-making. ***The Quality Standard Newsletter***, June 2018. https://www.aacqa.gov.au/providers/education/the-standard/june-2018/survey-and-guidelines-dementia-and-decision-making

Sinclair, C. (2019). Supported decision-making: Human rights and emerging practice. ***Australian Journal of Dementia Care***. (Dec 2018-Jan 2019 issue). https://journalofdementiacare.com/decemberjanuary-2019/

Other

Sinclair, C., Blake, M. (2018). **Human rights, dementia and supported decision-making**. Webinar recording 1/8/2018. Available from http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php

Sinclair, C., Pietsch, A., Agar, M. (2018) **Supporting decision-making for people living with dementia**. Webinar recording 13/8/2018. Available from http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php

Sinclair, C., Radoslovich, H., Williams, K. (2018) **Supported decision-making for aged care providers**. Webinar recording 30/8/2018. Available from http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php

Kurrle, S. (2018). Social Issues: **Supported decision-making for people living with dementia**. Interview on ABC Radio 23/11/2018. Available on http://radioadelaide.org.au/2018/11/23/supported-decision-making-for-people-living-with-dementia/

Cognitive Decline Partnership Centre (2018). **Theresa's story**. [Multimedia] Available from http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php

Cognitive Decline Partnership Centre (2018). **Jeanette and Ray's story**. [Multimedia] Available from http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php

Cognitive Decline Partnership Centre (2018). **Karine's story**. [Multimedia] Available from http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php

Cognitive Decline Partnership Centre (2018). **Ron's story**. [Multimedia] Available from http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php

Cognitive Decline Partnership Centre (2018). **Enabling choice in the context of risk**. [Multimedia] Available from http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php

Sinclair, C., & Field, S. (2018). **An introduction to Supported Decision-Making for aged care providers: Participant Workbook**. Accompaniment to training package. Cognitive Decline Partnership Centre: Sydney.

Cognitive Decline Partnership Centre (2018). **Supported decision-making: Help and assistance for decision-makers and supporters**. Available from http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php

Cognitive Decline Partnership Centre (2018). **Supported decision-making: Help and assistance for decision-makers and supporters (Italian translation)**. Available from http://sydney.edu.au/medicine/cdpc/documents/resources/SDM_Helpsheet_Italian.pdf

Cognitive Decline Partnership Centre (2018). **Supported decision-making: Help and assistance for decision-makers and supporters (Greek translation)**. Available from http://sydney.edu.au/medicine/cdpc/documents/resources/SDM_Helpsheet_Greek.pdf

Cognitive Decline Partnership Centre (2018). **Supported decision-making: Help and assistance for decision-makers and supporters (Mandarin translation)**. Available from http://sydney.edu.au/medicine/cdpc/documents/resources/SDM_Helpsheet_Chinese.pdf


COGNITIVE
DECLINE
PARTNERSHIP
CENTRE
THE UNIVERSITY OF
WESTERN
AUSTRALIA
dementia
australia
Brightwater
HammondCare
An independent Christian charity
Helping Hand