

Supported decision-making: human rights and emerging practice

Craig Sinclair shares current thinking about the importance of supported decision-making for people with dementia – and introduces new resources to support practice in this area

Supported decision-making is an emerging area of practice that is grounded in an increasingly prominent disability rights movement. The Convention on the Rights of Persons with Disabilities (CRPD) establishes an equal right to legal capacity for people living with disabilities (United Nations 2006). The CRPD provides a human rights framework, which calls on governments around the world to ensure that people living with disabilities are recognised by the law on an equal basis with others, and that they have access to support in making

decisions and exercising their ‘legal capacity’.

The voices of dementia advocates, in particular people with lived experience of dementia, have been critical in drawing global attention to the relevance of the CRPD for people with cognitive disabilities such as dementia (World Health Organization 2015; Swaffer 2018), and the need for governments and the community to provide supports that enable people to live well with dementia.

This article explores national and international developments on the topic of supported decision-making, and explores

recent research findings with implications for how this emerging practice might be implemented in dementia care.

What is supported decision-making?

Supported decision-making has been defined as “the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters” (United Nations Office of the High Commissioner on Human Rights 2009 p15). Supported decision-making is more than just ‘helping someone to make a decision’. In the context of

disability rights theory, it means understanding that a person’s impairments (eg in the case of dementia perhaps a cognitive, language and/or memory impairment) are not the sole cause of the person’s experience of disability. Instead, disability is seen as an interaction between a person’s impairment, and the community’s collective ability to accommodate that impairment, in order to ensure their full and effective inclusion and participation (Shakespeare *et al* 2017).

Thus just as hearing aids or wheelchair ramps can accommodate the needs of

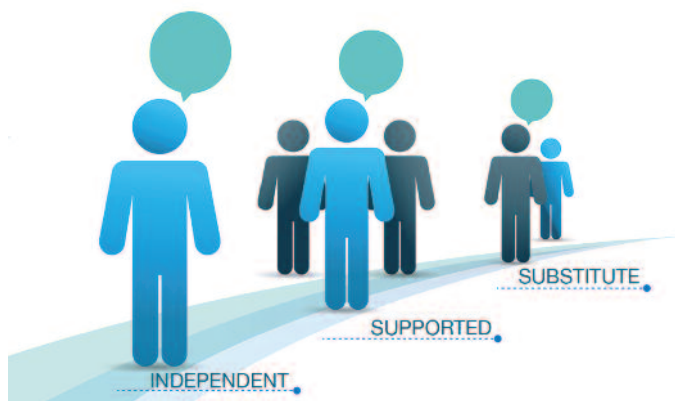


Figure 1: A spectrum of decision-making styles, as described by research participants. Source: Cognitive Decline Partnership Centre

people with sensory or physical impairments, supported decision-making includes (but is not limited to) the range of practical steps that can accommodate a person's impairments and enable them in making decisions about their lives.

The supported decision-making approach directly challenges the view that a person with a disability is 'incompetent', or should be excluded 'for their own protection or wellbeing'. Instead it acknowledges that each person has unique decision-making abilities, and unique needs for support, in order to exercise their right to legal capacity on an equal basis with others. Having signed and ratified the CRPD and its accompanying 'Optional Protocol', Australia is obliged to ensure that legal systems and frameworks are in place to ensure that these rights are observed.

This is an interesting challenge in a federated system like Australia, where different laws relating to decision-making and guardianship are in place across the different states and territories. However, a United Nations Committee, in its assessment of the current situation, determined that Australia's Government should "...take immediate steps to replace substitute decision-making with supported decision-making..." (United Nations Committee on the Rights of Persons with Disabilities 2013). The Australian Law Reform

Commission's (2014) report made a number of recommendations for changes in domestic laws, to begin the process of implementing supported decision-making. A small number of pilot programs have commenced, and Victoria has introduced a formal framework for supported decision-making, through provision of a 'supportive attorney' for financial decisions and a 'medical support person' for healthcare decisions (Victorian Office of the Public Advocate 2018).

Supported decision-making and dementia

Supported decision-making has been more widely used, over a longer period of time, in the context of developmental disabilities, than for people living with dementia. However, this disparity is now

being addressed. A Cognitive Decline Partnership Centre funded team, including researchers and consumer representatives, has been investigating supported decision-making in the context of dementia, focusing particularly on healthcare and lifestyle decision-making. A number of studies are underway, investigating Australian laws, the policies of Australian aged care organisations, and interviewing people living with dementia, their family members and professionals involved in dementia care.

This research has illustrated that both people with dementia and their family members place a high value on maintaining involvement in decision-making. Maintaining involvement and being included by others (particularly close family members and friends) has been shown to relate not only to a person's individual sense of purpose, self-worth and identity, but also more broadly to their ongoing sense of belonging and 'relational' identities (eg as a partner, parent or friend) (Sinclair *et al* 2018).

Through these interviews, we have observed that 'supported decision-making' is already happening in the community, at least on an informal basis. Rather than

decision-making being solely 'independent', 'supported' or 'substituted', decision-making involvement was occurring on a spectrum (see Figure 1), and influenced by factors relating to the individuals involved, their relationships, the decision itself, and external factors relating to the environment. These factors were dependent on the context, and changed over time (both progressively and also fluctuating from day to day).

We have also observed the importance of people's trusted relationships, as the social context and 'engine room' in which meaningful decisions are made. This shows the importance of the social context in decision-making, in addition to other factors related to the dementia process. Given that many people living with dementia also experience declines in their social networks and an increased reliance on key relationships, this points to the importance of acting at a community and societal level to address stigma and discrimination, and ensure full and effective participation in the broader community wherever possible.

Practical strategies

People living with dementia and their supporters have described a range of practical

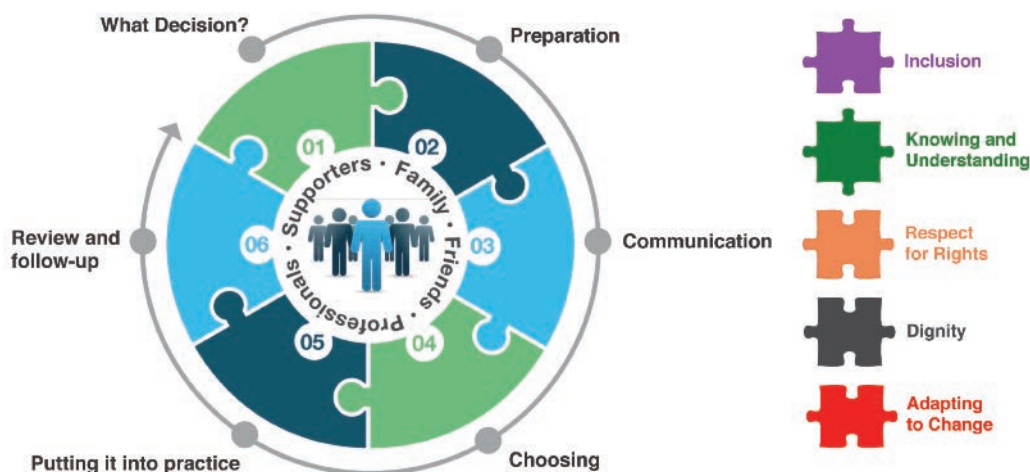


Figure 2: A process (left), and set of overarching values (right), to inform supported decision-making. Source: Cognitive Decline Partnership Centre

strategies they use to maximise involvement and participation, including things like:

- Prompting: identifying an opportunity for decision-making, or providing reminders about decisions that need to be made.
- Encouraging: help from other people to get motivated with making a decision.
- Providing ideas: providing suggestions or giving examples of the sorts of decisions made by other people.
- Interpreting: help to translate unfamiliar words or complex jargon into understandable language.
- Listening: listening to a person as they talk through their ideas, being a 'sounding board' and providing emotional support.
- Questioning: asking questions about a planned decision, to raise potential problems or another point of view.
- Affirming: providing reassurance about the decision and helping the person to put it into practice.

Based on these strategies, and what our participants told us they valued most, our team has developed a suite of resources that introduce a guiding model for a supported decision-making process, along with a set of key values, which underpin each stage of the process (see Figure 2). We suggest that this should be seen not as a strict, linear, or tick-box approach, but instead as a series of considerations to think about at each stage of the process. The overarching values of inclusion, knowing and understanding the person, respect for rights, dignity and adapting to change are important throughout the process.

Problems and pitfalls

While the developments around the CRPD and implementation of supported decision-making are

undoubtedly promising, and arguably better reflect the needs of people living with dementia, there are a range of potential issues that practitioners and the community need to be mindful of. These include:

- adequately resourcing decision-making support
- training care providers in supported decision-making strategies
- educating the community about supported decision-making
- safeguarding against potential undue influence from supporters
- inconsistent laws across Australia.

Practical resources

Through this research and the extensive input of advisory groups across three states in Australia (WA, SA, NSW), our team has produced a number of resources aimed at assisting practitioners and the community in understanding and implementing supported decision-making more formally in dementia care. These include:

- A policy guideline document for Australian aged care providers.
- A guidebook for people living with dementia, their family members and carers.
- A series of short videos describing lived experiences of supported decision-making and practical strategies.

A three-part webinar series aimed at understanding (i) the human rights and legal basis of supported decision-making, (ii) the practical principles and strategies for supported decision-making in the context of dementia, and (iii) the implications of supported decision-making in the aged care context.

All of these resources are freely available on the CDPC website, on our project resources webpage, which can be found at <http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php>

What next?

For any staff working in organisations providing care for people living with dementia, we recommend a review of your organisation's existing policies in the area of supported decision-making.

For those in aged care contexts (both community and residential), our research has generated a policy guideline document, which includes a self-assessment audit tool and framework for policy review and development. This guideline, *Supported decision-making in aged care: a policy development guideline for aged care providers in Australia*, has recently been promoted by the Australian Aged Care Quality Agency, and included in the resources relevant to incoming standards for aged care providers (Australian Aged Care Quality Agency 2018).

It is also important that similar processes of policy review are undertaken for organisations providing services in community settings, including those accessed by people with younger onset dementia.

Our ongoing efforts have included working with a range of partners and stakeholder organisations to convene a research and policy forum, held on 15 October. This forum aimed to generate consensus recommendations regarding the role of supported decision-making in the forthcoming National Plan to address elder abuse (Attorney-General for Australia 2018). The report and recommendations arising from the forum are available here: <http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php> ■

For further information on this work, visit the Cognitive Decline Partnership Centre website: <http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php>

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