

# **Discussion Paper**

Calling for development of a

## **National Supported Decision Making Framework**

Prepared on behalf of the Australian Supported Decision Making Network

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## **The Australian Supported Decision Making Network**

This paper has been prepared by the Australian Supported Decision Making Network (the ASDMN). The ASDMN began during 2012 to facilitate the implementation of supported decision making in Australia. The ASDMN currently has more than 100 members including people with disability and their families as well as members drawn from a wide range of agencies including service delivery, advocacy, government, academics and community sectors working in disability, older persons and mental health across Australia. Government members contribute on the basis that their input is not taken to commit their government to a particular course of action. The ASDMN has become a focus of expertise in supported decision making because of members' association with trial projects, research, and implementation of changed legislation. The network has met regularly over the past 3 years to share information on the latest work in SDM, consider wider policy issues and collaborate on the effective introduction of SDM across Australia.

Development of this paper was undertaken by a small reference group of members, led by the ACT Disability, Aged and Carer Advocacy Service. The paper has been endorsed for release by ASDMN members.

In early 2015 the Network wrote to Premiers and the Prime Minister advising them of the intention to prepare this discussion paper. Responses from jurisdictions acknowledged the contribution that a National Framework could make to achieving outcomes for people whose decision making ability is questioned.

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# National Supported Decision Making Framework

## Discussion Paper

This discussion paper describes supported decision making, what it is, how it works and why it's important. It calls for the development of a National Framework for supported decision making which would establish Australian practice. A National Framework is required because SDM has implications for a broad range of policy areas across multiple levels of government that reach into people's private lives.

Supported decision making supports people to exercise their ability to make legal and day to day decisions. Ensuring people have the support they need to engage in decision making is central to Australia's obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)<sup>1</sup>. In addition much Australian policy now recognises that people with disability have the right to choice and control in their lives, including the NDIS, reforms of mental health legislation, reforms of guardianship law, the National Disability Strategy and consumer directed care for older Australians. Currently, while high level policy statements recognise the right to exercise will and preference, the support needed by those whose decision making ability is impaired to exercise those rights is largely missing. There are isolated examples of good practice.

Supported decision making has applicability across a wide population including people with disability, people who experience mental health issues and people who experience aging conditions such as dementia. While we all access support for some decisions (from family, friends or professionals), people who are perceived to not have capacity for decision making are commonly denied the additional support that they need and decisions are made by substitute decision makers instead.

The breadth of the impact of supported decision making indicates the need for a National Framework to align responses across multiple disciplines and jurisdictions. It would also ensure consistent application of, and access to SDM. The elements of the National Framework are identified below and include ensuring that clear responsibility for legislation, regulation, policy and practice is articulated. It is the responsibility of governments at all levels to collaborate with other stakeholders in developing and delivering a National Framework for supported decision making.

The term 'supported decision making' (SDM) refers to a very broad range of practices and concepts. What is understood by the term 'supported decision making' has been shaped across a range of sectors, including the law, health, human rights and community sectors, each with its own interests and motivations.

The United Nations Office of the High Commissioner for Human Rights (OHCHR)<sup>2</sup> describes SDM as "the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters."<sup>3</sup> The United Nations Committee on the Rights of Persons with Disabilities has called for the replacement of guardianship systems with supported decision making

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<sup>1</sup> According to the UNCRPD persons with disabilities include those who have "long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

<sup>2</sup> The United Nations Office of the High Commissioner for Human Rights is a part of the United Nation's secretariat which promotes and protects human rights. See: <http://www.ohchr.org/EN/Pages/WelcomePage.aspx> for more information.

<sup>3</sup> United Nations Human Rights Council, 2009, para. 45.

responses and articulated features of a supported decision making regime which would be consistent with international human rights law.<sup>4</sup>

The Australian Law Reform Commission Report into Equality, Capacity and Disability in Commonwealth Laws<sup>5</sup> proposes National Decision Making Principles which provide a basis for change. A National Framework for SDM would engage policy makers, governments and other stakeholders in articulating a common vision for implementation of the National Decision Making Principles.

A National Framework would also contribute to delivery of outcomes under the National Disability Strategy<sup>6</sup> which recognises as areas for future action the need to review restrictive legislation and practices from a human rights perspective (2.4) and ensure supported decision making safeguards for those people who need them are in place, including accountability of guardianship and substitute decision makers (2.12).

## **What is Supported Decision Making?**

In Australia SDM is emerging across the community in a number of forms. Some Australian SDM projects have identified a range of shared steps involved in SDM, including:

- Building capability to recognise the role of decision making, the right to equality and self-determination
- Learning about decision making
- Recognising and expressing a decision
- Identifying and establishing support
- Exploring a decision
- Accessing information to inform a decision
- Advocating for the decision
- Fulfilling the decision
- Ongoing support for another decision.

Although this gives us some idea about what is involved in the practice of SDM, these steps also demonstrate that the supports a person uses will be decision and time specific, and will need to be adjusted according to the complexity of the decision. Some people may need support for all of the steps, others may only need support with one of the steps. As a safeguard, supported decision making should be available to people when and where they need it and be provided in a manner that optimizes their understanding and their decision making ability and participation.

Supported decision making can:

- Be an alternative or an adjunct to guardianship or administration
- Enable people to retain their legal capacity through being an alternative to enduring documents or powers of attorney as well as enable people to make arrangements of their choosing to be implemented in the future if required (advance directives).

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<sup>4</sup> UN Committee on the Rights of Persons with Disabilities General Comment No 1 (2014) paragraph 25

<sup>5</sup> <https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>

<sup>6</sup> <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020>

- Be a means by which a person can exercise their decision making ability with support; such as in mental health care and treatment decisions where it can be an alternative to involuntary treatment orders
- Enable people to access a range of other rights including having equal access to healthcare; by being active participants in health care decisions
- Support access to housing, legal, financial, telecommunications and other services
- Extend into people's personal lives to make decisions around who they live with, their supports and services, meaningful employment and the activities they participate in
- Enable people to have self-determined relationships, to enjoy a right to privacy and dignity, and the fulfilment of other social and cultural rights.

## **Developing a National Framework for SDM**

People who have impaired decision making ability, whose decision making ability is simply not recognised or whose decision making ability is declining may all benefit from access from SDM which is tailored to their individual needs and circumstances. The Framework should establish flexible, innovative responses able to meet this diversity.

The ALRC has recommended a set of National Decision Making Principles which provide a sound foundation for the Framework. The Principles are:

Everyone has the right to make decisions that affect their life and have those decisions respected.

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

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

Decisions, arrangements and interventions for persons who may require decision making support must respect their human rights.<sup>7</sup>

The ALRC recognises that there may be some circumstances when another person may be required to make a decision and terms this 'representative' decision making. Representative decisions are still made on the basis of will preferences and rights of the individual rather than the best interest model currently used by substitute decision makers. There are emerging models of practice both nationally and internationally that recognise decision making ability on a spectrum which requires a spectrum of responses between autonomous decision making and substitute decision making. The Framework needs to articulate good practice across this spectrum and provide practical guidance for implementation consistent with the principles.

These principles must also translate into other legislative, regulatory and policy frameworks and practices. The Framework should describe both the formal and informal implementation of SDM and the role of supporters.

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<sup>7</sup> Accessed at <http://www.alrc.gov.au/publications/equality-capacity-disability-report-124> on 18 Dec 2015

The Framework should articulate a common understanding of SDM which will enable a consistent, repeatable and accessible practice throughout Australia.

## **Stakeholders – community engagement**

The range of stakeholders for a National Supported Decision Making Framework is very broad. They include:

- People living with disability that leads their decision making ability to be questioned regardless of diagnosis, age, gender, culture, language.
- Family, friends and supporters of people with disability
- The Australian, state and territory governments
- Local governments
- Legal systems
- The National Disability Insurance Agency
- The disability and mental health service sectors (public, private and NGO)
- The Australian services sectors including legal, health, housing, education, retail, financial, employment and community
- All members of the Australian community

Engagement for each stakeholder group will vary. Ownership of the Framework would ideally include commitment from all governments on behalf of the Australian community. A genuine co-design approach, driven by a lead agency and SDM champions, to development of the Framework would involve diverse strategies to ensure the voice of each stakeholder group is heard and informs development. International experience highlights the importance of identifying an agency with responsibility for ensuring SDM practice is sustained and available to those who need it.

## **Safeguards – reporting, regulation and oversight**

Supported decision making is itself a safeguard of the assumption of a persons' decision making capacity and their right to make decisions. Recognising that in an SDM model, the decision belongs to the decision maker and responsibility for the decision is retained by the person, safeguards need to be described at a number of levels.

Safeguards for the SDM process should:

- Ensure that SDM practice is consistent with the Principles
- Enable SDM to be measured and evidenced
- Clarify legal risks, assurances and remedies available to decision makers and supporters
- Include a quality framework
- Provide oversight of SDM processes, including review mechanisms
- Clearly articulated responsibility for oversight

Safeguards for people using SDM should:

- Ensure that all people have access to SDM when and where they need it
- Include training and skills development for decision makers, supporters and organisations including responsibilities, boundaries of role and access

- Ensure that the use of SDM enables people to live a rich and varied lifestyle and develop skills while promoting personal and social wellbeing
- Balance duty of care and dignity of risk

Safeguards for supported decisions should:

- Ensure that safeguard responses are proportionate to the context of the decision being made and the impact in a person's life
- Include good practice guidance that ensures decisions are fully informed

While guardianship and administration systems are generally viewed as necessary safeguards for protected persons, it is important to remember that in the Australian context there is no long term study which measures the impact of guardianship in people's lives, and describes the ways in which guardianship is both a safeguard and a risk to safety or wellbeing of individuals.

The introduction of SDM provides an opportunity to put in place a safeguarding framework which prioritises the will, preferences and rights of a person in the context of promoting personal and social wellbeing.

## **Risk**

The goal of decision making strategies cannot be to eliminate all risk. Rather it might best be expressed as maximising the person's decision making potential and autonomy while keeping risk to an acceptable level.

It is important to recognise that existing mechanisms designed to keep people safe, including mechanisms which limit involvement in decision making, have the potential to be, of themselves, risky. A decision that a person cannot take part in an activity that may present physical risks for instance, may introduce risks associated with the person's mental health and co-existing difficulties, self-esteem, social isolation, emotional regulation and increase the likelihood of other risk taking behaviours. The benefits of SDM which have been identified through work to date include reduced risk of exploitation, abuse and neglect; greater autonomy; greater self-esteem; confidence and skill. These, along with dignity of risk and a person's right to make their own decisions, need to be balanced against perceptions of risk based in duty of care obligations. This balance may be achieved by enshrining supported decision making in law and policy, giving it comparable status to duty of care, and requiring evidence of supported decision making being unsuitable before substitute or representative decision makers are appointed. This change in focus, such that duty of care is not seen as sufficient rationale for representative decision making will be key to full implementation of SDM, based in a presumption of decision making ability. The National Framework provides an opportunity to articulate a new approach to risk in decision making which presumes capacity and ensures that safeguards which enable decision making are developed.

## **Language – consistency, availability and equal access**

The Framework is an opportunity to establish consistent language to describe SDM which would underpin consistency in law, practice and participation. Areas needing further exploration include

- Formal and informal decision making
- Legal capacity and decision making ability

- Support for decision making and support with decision making
- Assisted decision making, co-decision making and supported decision making

## **Resources – capability building and funding**

Implementation of the ALRC Principles ensuring SDM is available to those who need it does not come without cost. Governments will ultimately bear some responsibility for establishing and supplying supported decision making, oversight and monitoring. In addition, different levels of the community can enable supported decision making by changing existing practices to ensure people's right to participate in decision making. It should be recognised that Guardianship, for example, does not come without cost. There will be some new resources needed for SDM, but also some realignment of existing practices so that they become consistent with the CRPD.

Recognising that wider community development and social inclusion activities will promote SDM, a National Framework could establish capability building resources and principles for funding of supported decision making. Without establishment funding SDM is less likely to become well embedded and widely available in the community.

## **Innovation**

The Framework should support innovation by

- Recognising SDM as a tool to build decision making ability, respond to fluctuating decision making ability and prepare for declining ability.
- Upholding principles of co-design so that models are responsive to experiences of all stakeholders, particularly decision makers and their supporters.
- Identifying mechanisms for continuous improvement

Innovation within the Framework itself may be achieved through inclusion of a structured review mechanism (perhaps biennially) which enables new research and practice insights to be built into the Framework.

## **Sustainability**

Community wide capacity building which recognises that everyone has a responsibility to enable decision making where and when it is needed will be pivotal to sustainability of SDM. Embedding SDM will require relationships between SDM and legal decision making mechanisms to be clearly articulated. The National Framework could consider the relationship between SDM and advance directives, enduring power of attorney, and appointments of substitute decision makers (including guardians and trustees) under varied legal frameworks. This will have implications for other policies that intersect with these mechanisms, for example Health Law.

Through enactment of a legislative response to SDM, sustainability models could emerge.

CRPD preferences freely given decision support over paid support. Whilst the decision supporter role will ideally be freely given, sustainability will require investment in:

- Outreach for socially isolated people
- Mentoring and coaching



- Community wide training and skills development for decision makers and decision supporters
- Oversight and monitoring
- Gathering the evidence base
- Evaluation and innovation

A National Framework would establish mechanisms for sharing of expertise and SDM resources, reporting on implementation of SDM and action plans which would sustain momentum of implementation.

Successful development and implementation of the Framework will require a community development approach, which includes genuine engagement of disability peoples' organisations, carers and others in the community sector.

## **Evaluation**

Frameworks should be consistent with the national decision making principles, the National Disability Strategy and the UNCRPD.

The experience of people with disability must be at the centre of an evaluation process. In addition, understanding the perspectives, motivations and challenges for decision supporters will contribute to sustainability.

A National Framework would establish the high level evaluation framework and mechanisms for data collection and reporting to inform evaluation, as well as feedback loops which ensure that evaluation findings inform further development of SDM practice.

## What comes next

This paper has sought to identify the key issues on which implementation of supported decision making rests. These issues require both attention and investment to explore them in greater depth, provide more detailed analysis, and reach a common understanding which will contribute to implementation of the ALRC recommendations for law reform as well as the development of a National Framework for SDM and full implementation of supported decision making across Australia.

All levels of Government in Australia need to make a commitment to establishing the SDM Framework. The National Supported Decision Making Network will work cooperatively with Governments in development of the Framework. Initial actions might include

- Establishment of a national advisory committee on supported decision making tasked with driving the SDM agenda forward
- Identifying and recruiting high profile champions for the National Supported Decision Making Framework.
- That Governments respond to the ALRC Capacity Inquiry regarding law reform and commit to a community development approach, working with civil society, to implementation of SDM
- Establish mechanisms for integration of community practice through pilot projects around the country in collaboration with academic research and policy/legislation development
- Development of an integrated evidence base through further research that recognises the expertise and experience of people with disability, their families and supporters, the community sector, as well as the academic sector in growing knowledge about SDM.
- A national supported decision making conference which brings together a wide range of stakeholders for an in depth discussion of supported decision making issues