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UNIVERSITY

LIVING WITH DISABILITY
RESEARCH CENTRE



Making supported decision making happen for people with intellectual disabilities: the scale of the task

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Talking about why supported decision-making is important



Living with
Disability Research
Centre



See clip on CID website

Making up for lost time

- Lot of ground covered since 2006
- Moved beyond theoretical debates about supported decision making (SDM)
- Widespread acceptance
 - Need for formal legal reform
 - To embed SDM practice in service systems and expectations of all supporters
- SDM featured in the Royal Commission report –more on Guardianship than everyday support
- Recommendations 10.6 amend practice standards of disability services to include SDM
- SDM now in NDIS policy – Royal Commission critiques it as not strong enough
- SDM becoming part of policy rhetoric holds dangers – history of visionary policy poorly implemented

Research Report

Diversity, dignity, equity and
best practice: a framework for
supported decision-making

The Living with Disability
Research Centre, La Trobe University

January 2023

What needs to be in place and scale of the task ahead

- Research for Royal Commission
- Literature review
- Interviews with 79 people - cross section of stakeholders
- Synthesised - 9 principles and 8 elements
- Focus on
 - Clarity about SDM- a principled approach
 - Scale of practice change needed – why practice is difficult
 - Components of best practice

Universal Principles

- Principle 1.** The equal right to make decisions
- Principle 2.** Support
- Principle 3.** Will, preferences and rights
- Principle 4.** Safeguards
- Principle 5.** Principled approach to supported decision-making
- Principle 6.** Best interpretation of will and preferences
- Principle 7.** Dignity and risk
- Principle 8.** Distributional equity
- Principle 9.** Co-leadership of people with cognitive disabilities

Elements

1. Recognising diversity in supported decision-making
2. Interrelationships with other systems
3. Use of best practice and ethical supported decision-making
4. Capacity building at individual, system and institutional levels
5. Safeguarding, quality assurance and oversight
6. Mechanisms for advance planning
7. Adequate funding
8. Strategies to build social connections

Clarity about supported decision making ?

- Competing views about SDM

...a lack of clarity about difference between substitute decision making and supported decision making. A lack of consistency with supported decision-making even in Australia between state legislation

- Does it matter ?
- How SDM is understood has implications for
 - How it is practiced – expectations of supporters – training – evaluating progress
 - Whether SDM applies all the time to everyone
 - Whether decision making ability or ‘capacity’ ever comes into question
 - What safeguards are put in place and when
- Identified 3 perspectives from our interviews and the literature

1 Binary Approach

Either supported decision making

- Retains control and actively participates
- Is supported to explore options, implications and constraints
- Decisions based on the person's stated will and preferences
- Support tops up a person's ability to reach a capacity threshold

means you're in control of your decisions but still getting support while doing it (self-advocate)

process of providing support to people to make decisions to remain in control of their lives (NDIS)

Or substitute decision-making

- Cannot actively participate - even with support does not fully understand implications or needs a supporter to interpret their preferences
- Based on the person's 'best interests'

Some people will always need a substitute decision made – to pretend that a substitute is a supporter could lead to abuse (advocate-disability)

... you need to take over when someone clearly has not got capacity at that point. This needs to be part of practice or program design (advocate-disability)

Binary understanding of SDM

- Common sense approach
- Embeds notions of capacity and limits SDM to people who with support can reach a notional benchmark of decision making capacity to make an informed decision
- Excludes people with severe cognitive impairment from SDM

2. Something between SDM and Substitute

It's not quite substitute, it's not supported. There's something else there

- Removes best interests or reaching a threshold of capacity
- To include people severe cognitive impairments who do not use words or concepts to communicate
- But whose behaviour, actions or demeanour might be interpreted to demonstrate preferences

There is something in the middle where you are really trying to make a decision that's really honouring the person's participation and really trying to identify their wishes even when that's incredibly difficult but acknowledging that there's a whole heap of interpretation going on, so you can't be sure that that is what the person wants". (advocate-disability)

To call it 100% support is a fantasy – what about facilitated decision-making or representational decision-making" (family-disability)

New concept – where to put the boundaries?

3. Principled approach

Continuum of decision making supports

- Principles of SDM embedded in any form of decision support
- SDM applies irrespective of degree of participation or need for interpretation of will and preferences
- Persons will and preferences at centre of all decisions
- SDM includes some types of ‘substitute decision making’ based on will and preferences
 - ...so that supported decision-making is practised even when there is a guardian” *(advocate-carer)*
- The only circumstances where SDM principles would not apply - a clash of rights – between autonomy and safety
- Where there was serious risk of imminent physical or financial harm with lasting consequences if guided only by will and preferences
- In exceptional circumstances a substitute decision would be made guided by both will and preferences and personal and social wellbeing

Why a principled approach

- Removes the binary of SDM good and Substitute bad
- Stated or perceived will and preferences remain at the centre of decisions
- Includes people with the most severe cognitive impairments within SDM
- Recognises reality people may not participate or express preferences in standard ways and rely on others to make decisions on their behalf
- Creates imperative for all supporters to use SDM principles
- And not override will and preferences unless clash of rights result in serious harm
- Approach adopted by Royal Commission and some Australian legal reform

Scale of change needed to practice

- **Shift pattern of limited involvement decision making**

27 of the 28 participants with intellectual disabilities reported that a family member who supported them largely determined what was included in their plans, and at times overrode, failed to listen to or silenced the adult's own perspective.... (cited in Bigby, 2020)

- **Change everyday practice of supporters**

- Flips between support and best interests
- Often concerned with 'Making right decision'

...as long as they're not poor decisions because that's our job too to make sure that he's not making poor decisions (parent)

- Often means influencing, deceiving, manipulating, controlling, assuming

what I do is try and influence her to make the decision that I think she should make". (parent)

...she doesn't seem to give me the impression she really understands what the next step is. And I'm not sure I want to tell her...Well we're just going to string it along and have the sleep overs for a bit. (parent)

- **Lift expectations about accountability of supporters**

"there is little evidence that NDIA planners scrutinise the approach taken by supporters...

SDM practice is difficult

Onerous and emotionally demanding process

...it's really hard to be disciplined, to continue asking open-ended questions and continue to pass over responsibility. (parent)

- Narrow life experience mean little experience of decision making or options
- Difficulties with communication, and understanding abstract options, constraints or implications

I just am really conscious of the big picture that I'm trying to work towards for Sally when she might not have the capacity to think in those same big terms. (parent)

- Supports must also find strategies to
 - enable risk and avoid harm
 - remain neutral
 - manage conflicting interests - impact of decision on others
- Services systems must find supporters

Best practice – Prerequisites

- Practice frameworks - guide practice and accountability

Need a framework and process that people can follow. (advocate-disability)

- Multiple supporters – for transparency and checking

...because when you're interpreting will and preferences, you have your own lens, and someone else can interpret things differently – to suggest that there's an objective truth is unhelpful – need to wrestle with different interpretations. (service provider)

- Independent supporters

no one is independent, not the support coordinator, the NDIA, nor the service providers. Service providers can be good, but that's lucky rather than by design, so there is a need for an independent person. (advocate-generic)

- Relationships of trust
- Person and context specific knowledge
- Time

So, the risk is that in trying to do SDM in haste, or at arm's length, or shortcuts or whatever, there may certainly be cases where that's manageable, but certainly the clients we've dealt with, that would be a disaster. (advocate-disability)

Best practice frameworks - key components

- Most cited by participants - La Trobe Practice Framework
- Targeted at supporter's skills

Iterative steps

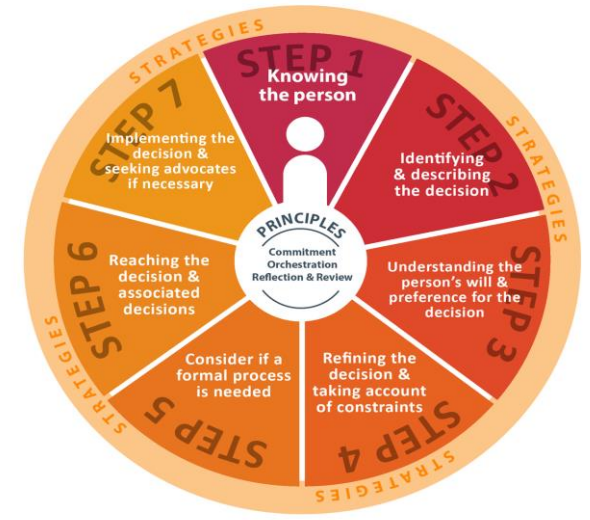
- Knowing the person
- Identifying decision and its parameters, exploring options
- Understanding will and preferences, refining to take accounts of constraints
- Determining need for formal process
- Reaching decision and associated decisions – implementing and findings advocates

Individualised strategies

- Listening, communication, checking, breaking down, experiencing,

Principles

- Objectivity and reflexivity
- Commitment to rights
- Orchestration



Taking account of diversity

Programs and practice take account of diverse groups **And** diverse social and cultural contexts

Need generic frameworks... allow for various forms of support to suit circumstances and needs. (family-disability)

You need the expertise of those who are more familiar with particular groups (Family-disability).

- Too soon to be prescriptive about programs and practice
- Further need for innovation and evidence about what works, in what contexts, for whom
- Specific attention to design in less individualist CALD and First Nations community settings

Tackle inequities

- New programs prioritise most disadvantaged - without family or networks or advocates

We're interested in that person who is really super-quiet and is no problem to anybody, because maybe that person doesn't have any family, and has needs that are just being ignored.... (Advocate-disability)

- Invest in evidence and strategies for network building

SDM cannot stand alone

SDM must reach beyond the disability sector

- People interact with multiple formal and informal systems
- Different jurisdictions and sectors - Different institutional and legislative frameworks
- Very different traditions of decision making and moving at different paces
- Need for SDM to be embedded in all of these
- Context specific SDM action plans and measures to take up of SDM in each sector

Capacity development

Tailored capacity building for supporters across sectors, professions and community

Need community to be more aware of good supported decision-making so it can lead expectations”.

(Advocate-disability)

Supporters need to be trained and understand influence and subtle coercion, and how to be objective and neutral” *(Advocate-generic)*

Capacity building of people with intellectual disabilities over their life course

Oversight and monitoring

- Potential for coercion or inappropriate influence by supporters (Kohn)
- Participants disillusioned with safeguarding effectiveness – better resourcing and creativity

*Just registration of provider with NDIS and quality audits are not enough...they have 'beautiful' policies".
(advocate-disability)*

- Network building a key strategy - *many eyes watching out*
- Tailor monitoring to different groups and settings – proportional to risk
- Wary of regulating informal supporters

Families shouldn't be treated the same as workers. (advocate-disability)

- Use education, training and financial incentives
- For formal supporters build competences into – professional codes of conduct or service standards and accreditation
- Use existing expertise of Office of Public Advocates

SDM Framework - Principles and Elements

- Universal principles

“...there's some pretty obvious principles that could be drawn from human rights documents and the idea that the support for a person should maximise their participation in decision-making, in a way that doesn't lead to their harm” (advocate-generic)

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Core to SDM ‘every person with intellectual disability is known well and socially connected to supporters who recognise their right to express preferences about all aspects of life and for their preferences to be respected and acted upon’. P. 164

Free on line training resources

The La Trobe Support for Decision Making Practice Framework Learning Resource

[ABOUT](#)
[MODULE 1](#)
[MODULE 2](#)
[MODULE 3](#)
[MODULE 4](#)
[MODULE 5](#)
[MODULE 6](#)
[RESOURCES](#)
[CONTACT](#)


About this resource

This online learning resource is about support for decision making. It will present the first evidence-based framework to guide you through the process of supporting people with cognitive disabilities to make decisions. Using this framework will help you to enable the people you support to exercise choice and control in their own lives.

<http://www.supportfordecisionmakingresource.com.au/>

Free on-line training resources

Enabling Risk
Putting Positives First

ABOUT

MODULE 1

MODULE 2

MODULE 3

MODULE 4

MODULE 5

RESOURCES

CONTACT



About this resource.

Enabling Risk: Putting Positives First is an online learning resource developed specifically for disability support workers.

<https://www.enablingriskresource.com.au/>

Practice Framework

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