



34 Stanley St
Collingwood 3066 VIC
P (03) 9416 4003
E info@valid.org.au

VALID Position Statement: Supported Decision Making (Summary)

VALID’s Supported Decision Making (SDM) Position Statement

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About VALID

[VALID](#) is the peak advocacy organisation in Victoria for adults with intellectual disability and their families. VALID empowers adults with disability through:

- [Individual Advocacy](#)
- [Self Advocacy](#)
- [Training Programs](#)
- [Community Development](#)
- [Having a Say Conference](#)

VALID has been run by and for people with disability and their family members for over 30 years. During this time, we have networked, shared information and run projects for and with people with intellectual disability and their families. You can learn more about VALID [on our website](#).

This statement is part of VALID's advocacy in fighting with and for people for their right to live the life of their choice.

Acknowledgments

We appreciate everyone who helped us write this statement, but especially people with intellectual disability and their families. Whether you responded to emails or came to consultations, we could not have written this statement without you. We understand this was not 'just' an academic or advocacy exercise for you, and we have tried to do this justice.

Consultant: What is an example of a decision you have made?

Person with disability: To come to this consultation on my own today.

Why Supported Decision Making?

VALID is writing this statement because all Victorian adults with intellectual disability deserve access to independent decision-making support. To be effective, this support must work with people, their families and supporters to make sure they are living empowered lives on their own terms.

Consultant: What rights are most important to you?

Person with disability: Treat people like normal people. Some people with disability are not treated the same.

VALID's position on SDM comes in part from consultations. In these, we were privileged to learn from the expertise of adults with intellectual disability, adults with disabilities other than intellectual, families, and advocates and supporters within VALID and the disability sector. We have changed identifying details where necessary.

The wisdom to understand what is not working with SDM comes directly from people with intellectual disability and their families, and people who work closely with and for them.

Consultant: Who supports you to make decisions?

Person with disability: Myself. My own heart.

We know how important it is to learn from people's lived experience. We also know that good work has already been done around SDM. So we built on this by gathering existing information and finding out what people thought and wanted to add through our own consultation process. You can find this process in the Appendix.

Consultant: What does support to make decisions mean to you?

Person with disability: I needed to change an appointment, I did it myself. I'm quite proud of myself. I need help sometimes, because [people supporting me] can explain things better.

Based on what we know and have learned, VALID believes many adults with intellectual disability have been denied appropriate decision-making resources and support for too long. So VALID is building on the legal and social momentum behind SDM to create this Position and our Call to Action to the National Disability Insurance Agency (NDIA), Victorian State Government, Victorian Disability Organisations, and people with intellectual disability and their families.

Everyone needs support to make decisions. But there are things that make decision making harder than it needs to be for people with intellectual disability. VALID is working to bring SDM to life in practice for all people with intellectual disability who consistently experience the worst of these things.

‘When [my supporters] challenge [my] decision to [engage in a hobby], I feel like I made a mistake. I totally shut down, that’s the hardest thing for me.’

Person with disability

Overview

There are serious problems with SDM

‘The real problem is not “supported decision making”. It’s that too many people with intellectual disability don’t have people in their lives who aren’t paid to be there.’

Advocate

In our consultation process, VALID heard that problems with SDM for people with intellectual disability exist partly because Western society tends to assume that most people make decisions independently and without support. This is not true: everybody needs support to make decisions. But this assumption means that when a person with intellectual disability needs this same support – perhaps at a different frequency or intensity – people assume they cannot make their own decisions at all.

This assumption is everywhere, and it harms everyone. It harms people with intellectual disability, because many rarely get the opportunity to learn from the benefits and consequences of their own decisions. It also harms taxpayers because the assumption that people with intellectual disability cannot make their own decisions has led to an expensive service system. This system encourages the assumption that ‘some people cannot learn to make their own decisions’.

Consultant: What support does not help you make decisions? What support is bad?

People with disability: Telling you what to do. Being rude. Not asking what we want. Doing things without talking to us.

This is a big problem. Although the discussion about SDM is current in Australia, it has mostly been happening in mental health and aged care – though the [Disability Royal Commission \(DRC\) Final Report](#) and [NDIS Review](#) have started to change this. But we still do not know the full scale of the problem. This is a real issue in part because so many problems for people with intellectual disability can be traced back to a lack of SDM.

But instead of understanding that we all need support to make decisions, we refer to this need specifically as one for people with intellectual disability. We then label this ‘additional’ support as ‘Supported Decision Making’. Even then, we do not meet this human need well or at all for many with intellectual disability.

Without SDM, **people frequently use their behaviour to express frustration and powerlessness.** This is usually labelled ‘behaviours of concern’ and treated as a problem with an individual instead of what can be a response to a lack of SDM that would give them more choice and control over their own lives.

A lack of SDM makes life bad for some people, and very bad for others. It is critical for this statement to emphasise the importance of SDM. But VALID cannot avoid discussion about very serious reasons why some people do not trust SDM. VALID has written a short case study that presents an extreme example showing why it is critical for anyone – but people with intellectual disability in this case – to have unpaid people in their lives who love and care about them, and to support them to make their own decisions. You can find this case study in **VALID’s Position Statement: Supported Decision Making Statement (Full).**

The good news? When people have resources, time and good decision-making support, their lives get better.

Consultant: What support do you need to make decisions that help you reach your goals?

People with disability: Have a good understanding between the person and support worker. Work together.

Why does VALID need a Position Statement on SDM?

Every other position VALID takes on issues that impact people with intellectual disability depends on their access to appropriate decision-making support. The need for this statement was also demonstrated through our consultations:

‘If a support worker said no [to going out when it is raining], I’d say isn’t that [worker] supposed to support them by getting a jacket, warm boots, etc.?’

Person with disability

How did VALID decide which principles to include?

VALID’s position on SDM was decided by working out which legal, human rights, and research we might support. Then we consulted with people with intellectual disability, families and advocates to discuss SDM in general and in the context of information VALID was considering for inclusion.

What do people with disability, families and advocates say?

Responses from **people with disability** were varied:

‘Toxic support is when they help you too much or when you begin to slowly rely on them. Like, you don’t think of things by yourself [when you’re being helped too much].’

Person with disability

‘I get help to cook tea. I make my mind up yesterday [about what to eat] and she helps me with it tonight.’

Person with disability

‘Do you want to answer the question?’

Support staff of consultation participant with disability, who did not respond directly when prompted

Some **families** who emailed VALID in response to questions we sent emphasised the importance of supporting their loved one’s decision-making. One family member emailed saying it is important to find a balance between SDM and duty of care:

‘Specialised decision support is needed in [very specific] situations.’

Family member

One **advocate** spoke about the importance of government acting on recommendations from the 2014 ALRC Principles:¹

‘Victoria has the most progressive supported decision making legislation. That doesn’t mean anything is being done about it.’

Advocate

Advocates talked about the gaps between ‘theory and practice’ and highlighted the lack of practical framework around SDM. This is concerning because appropriate SDM support is critical: **There can be no choice and control without support to make decisions.**

¹ Towards supported decision-making in Australia: www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/1-executive-summary-2/towards-supported-decision-making-in-australia/

VALID's Supported Decision Making Principles

Based on law, consultations and research, VALID's positions on SDM for people with intellectual disability are:

- 1. To uphold people's will, preferences and rights**
- 2. Safeguards**
- 3. To minimise conflicts of interest**
- 4. That capacity to make decisions must be assumed**
- 5. That people have the equal right to make decisions about things that affect them**

VALID's SDM principles are an empowering, nuanced reflection of our belief that people with intellectual disability have the right to appropriate support to make their own decisions. You can find more information about each of these, as well as legal gaps we identified, in **VALID's Position Statement: Supported Decision Making Statement (Full)** document.

'Don't do the decision for me, help me to make the decision.'

Person with disability

Appendix: Consultations

The consultation process started with us seeking initial information from people within and closely connected to VALID:

- What should VALID add to the conversation around SDM?
- What initial research should we do?
- What information exists that might inform our position?
- What issues are we best positioned to address?
- Who do we need to consult?

We prepared information about people's rights, entitlements and law in Plain and Easy English formats. We emailed this information to past and present VALID members. People were given the option to respond by email, phone or video call. Responses were factored into VALID's position.

We consulted with VALID's Self-Advocacy Forum, Peer Action Group (PAG) Leaders, multiple Self-Advocacy Networks, and three VALID8 groups to gather perspectives based on questions like:

- What does **making a decision** mean to you?
- What is an **example** of a decision you have made?
- What does **support** to make decisions mean to you?
- **Who** supports you to make decisions?
- What support **helps** you make decisions? What support is **good**?
- What support **does not** help you make decisions? What support is **bad**?
- Do you prefer to make decisions that **feel good now**? Or that help you **reach your goals**?
- Do you feel like it is **OK for you to change a decision** you make?
- Do you ever want people supporting you to **make a decision for you**?
- Do you feel like it is OK to **make a decision that other people don't like**?
- Do you feel like it is OK to **make mistakes and learn from them**?
- What **rights** are most important to you?
- Do you get to make **decisions that other people think are risky**?
- Do you think people supporting you should ever **decide something is too risky**?

This paper was drafted and redrafted based on responses to the consultation process that ran over 5 months.

We then shared this draft with VALID's Systemic Advocacy Advisory Group² to guide VALID on our calls to action. After translating the most important information from these into Easy Read, VALID's CEO and Board approved the final draft before publishing.

² William Ward-Boas, Gerard Langridge, Sarah Forbes, Naomi Anderson, Kevin Stone, Emily Piggott, Christian Astourian, Katherine Marshall.