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VALID Position Statement: Supported Decision Making (Full)

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About VALID

VALID's four main program areas are:

1. [Training and Consultations](#)

VALID's Training and Consultations team runs courses for people with disability, family members and support staff. This team focuses on empowerment, accessibility and safety of people with disability. They also run focus groups that give people with disability and their families a chance to be listened to on different topics that affect them.

2. [Self Advocacy](#)

VALID's Self Advocacy team supports people with disability in different ways to become strong self advocates. One of these is working with VALID staff with intellectual disability in the VALID8 teams. VALID8 and Self Advocacy review group homes and report on self-advocacy practice to the service provider and the Department of Families, Fairness and Housing (DFFH).

3. [Community Development and Engagement](#)

VALID's Community Development and Engagement team works to build more inclusive communities so people with disability can live lives of their choosing. They work to create change at individual, group and community levels in the community.

4. [Individual Advocacy](#)

VALID's Individual Advocacy team works with individuals to help solve a short-term problem they are having. They help people speak up about what they want, get the information they need to make their own decisions, and explore the choices they want to make. VALID also supports family members of people with intellectual disability as they advocate for or with someone.

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Andrew Minge, VALID Advocate, whose work with Sarah in creating VALID's position statement template has been important to VALID's ongoing systemic advocacy.

Kevin Stone, Advocacy Trainer, whose experience in the education and empowerment of people with intellectual disability and families has informed the development of this statement.

All other advocates we consulted with, whose collective experience and wisdom helped shape this statement. As a result, this document is informed by deep thought and an ongoing commitment to the fight for people with intellectual disability's right to supported decision making in both theory and practice.

Consultant: Do you feel like it is okay to make mistakes and learn from them?

Person with disability: No, there's guardianship orders that mean we can't afford to make mistakes.

¹ Supported Decision Making in Disability (contact VALID if you would like a copy)

² Office of the Public Advocate

Introduction

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 supported decision making (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 have built on this work by gathering existing information and finding out what people thought and wanted to add through our own consultation process.³

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 not had adequate decision-making resources and support for too long. This includes adults with very high communication support needs.

³ See Appendix.

This is why VALID is building on the legal and social momentum behind SDM to create this position: a position that will reinforce VALID's call to action to the NDIA, Victorian Government, disability sector, and people with intellectual disability and families.

This statement focuses on:

- The lack of **financial and human resourcing** behind SDM
- The lack of **framework** for SDM that can be used by people without informal support
- The lack of **education** around SDM for people with intellectual disability and their supported decision makers
- **The legacy of a status quo that sees the voices of people with intellectual disability violated, abused, neglected and exploited.**

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

Because everyone deserves the opportunity to live life on their own terms.

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

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

Executive Summary

‘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

Every other position VALID takes on issues that impact people with intellectual disability depends on their access to appropriate decision-making support.

Consultations VALID held with people with intellectual disability showed the need for this statement. Some people feel frustrated that their rights are still not translating into practice. One person expressed how vulnerable they feel when they know what they need but are not supported to get it. And others expressed themselves in ways that made it impossible for the consultant to understand their communication. All perspectives were considered equally in the development of this statement.

‘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

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

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

‘Society has moved on from protectionism. We can take people... on the journey, but it’s our choice.’

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

‘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 SDM questions we sent emphasised the importance of supporting their loved one's decision-making. We have used their quotes throughout this statement. 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.'

One **advocate** spoke about the importance of government acting on recommendations from the 2014 ALRC Principles:⁴

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

Multiple advocates spoke 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.

VALID thinks problems with SDM for people with intellectual disability exist in part because Western society assumes that most people make decisions independently and without support. Therefore, when a person with intellectual disability needs SDM, people assume they cannot make their own decisions. But when people have resources, time and good decision-making support, their lives get better. Without SDM, people frequently use their behaviour to express frustration and powerlessness. This is usually labeled as 'behaviours of concern'.

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.

⁴ 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/

This is a big problem. Although the discussion about SDM is current in Australia, these discussions have been mostly happening in mental health and aged care – though the [Disability Royal Commission \(DRC\) Final Report](#) and [NDIS Review Final Report](#) are recent and welcome developments. But we still cannot tell you the full scale of the problem, despite this recent research that includes a focus on SDM and intellectual disability. 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. So we have presented / referred to the little data we have and written a case study that shows a common problem VALID sees when SDM is not done well or at all.

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.

This problem 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’.

This problem 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 distrust SDM. We have included a short case study as an extreme example that shows 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.

Based on law, consultations and research, VALID’s position on SDM for people with intellectual disability is:

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**

A legal system that enforces the human right of people with intellectual disability to make their own decisions is a critical starting point. But **legal gaps** fail to touch at least 5 realities of people's lives:

1. **The lasting impact of inaccurate assumptions**
2. **No resources**
3. **No standard or framework**
4. **Inaccurate and inhumane financial analyses**
5. **SDM dilemmas compromise support staff**

'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

Why is SDM important to VALID?

‘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

Every other position VALID takes on issues that impact people with intellectual disability relies on their access to appropriate support to make their own decisions. So we are building on the momentum of recent SDM research and policy responses to help support and turn these into action.

‘If there aren’t practical resources to make SDM happen in the real world, then no law or policy can change anything.’

Disability Consultant

What isn’t working?

‘Bad decisions is a human thing to do.’

Person with disability

Everyone with intellectual disability has the same right as anyone else for support to make decisions that affect their own lives. This right is in the Charter,⁵ the UNCRPD,⁶ the NDIS Act 2013⁷ and the Guardianship and Administration Act 2019.⁸ Therefore, it is very clear that the problem is not that people don’t have the legal right to make decisions. This is good news.

⁵ United Nations Charter: www.un.org/en/about-us/un-charter

⁶ United Nations Convention on the Rights of Persons with Disabilities (UNCRPD): www.humanrights.gov.au/our-work/disability-rights/united-nations-convention-rights-persons-disabilities-uncrpd

⁷ Legislation: www.ndis.gov.au/about-us/governance/legislation

⁸ Guardianship and Administration Act 2019: www.legislation.vic.gov.au/in-force/acts/guardianship-and-administration-act-2019/007

The problem is that despite having the **legal right** to make their own decisions, many people with intellectual disability **do not have access to appropriate SDM**. This is a problem for many reasons. One is that when people with intellectual disability engage with the NDIA,⁹ they are often not supported to understand what is happening. This often results in other people making decisions for them.

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

Person with disability

We are pleased that the NDIA’s Supported Decision Making Implementation Plan (April 2023)¹⁰ touches on key issues we discuss in this paper. However, this Plan does not address two important issues:

1. Many disability workers do not demonstrate an understanding of SDM

‘There is no framework around SDM in Victoria. So [advocacy organisation] gets calls from Support Coordinators asking about guardianship around decisions about things like where a person should live. SDM would be far more appropriate in these cases.’

Advocate

This tells us that not having a framework for SDM is a problem. That is because even well-meaning workers will naturally default to a more accessible option over the more appropriate one. And this assumes that workers are aware of SDM at all, which not all are.

⁹ National Disability Insurance Agency

¹⁰ NDIS Supported Decision making Implementation Plan:
www.ndis.gov.au/media/5897/download?attachment

2. No independent SDM exists in Victoria

‘We can talk about funding and write policies around SDM, but how can you reduce conflicts of interest when there is nobody independent to provide that support?’

Advocate

From 2017, VALID’s Choice Mentor Program ‘support[ed] people with a disability who have limited support in their life from family or friends, to build their capacity to make decisions about their own life’.¹¹ This program ended in 2021 because of lack of funding, but no equivalent program exists in Victoria. This is an issue for all disability workers: even for those who are aware of SDM, there is no independent support to call on.

‘If my focus wasn’t on whether my family member’s choices are being respected, then nobody being paid to support them would ask them what they want.’

Family member

This indicates that people with intellectual disability whose family members have a different focus, or people with no informal support in their lives, may never get asked what they want.

Lack of opportunities for people to have different experiences

VALID knows that adults with intellectual disability have had decisions made for them for a long time. When we asked in one consultation for people with intellectual disability whether anyone thought people supporting them should decide something is too risky for them to try, one person said yes.

Note-taker in consultation: Does that include the travel training you’ve done?

Person with disability: I wouldn’t know any better and would have stayed in local areas.

¹¹ VALID Choice Mentors: www.valid.org.au/sites/default/files/VALID%20A5%20Brochure%20-%20Choice%20Mentor%20FINAL.pdf

Part of the reason law and policy alone cannot change this is because historically, supporting people with intellectual disability to make their own decisions has not been how things are done.¹²

Consultant: Do you like making decisions that help you reach your goals?

Person with disability: I haven't had a chance to make those decisions yet.

As this experience (or lack of) gradually changes for people, we need to do more than examine laws and policies that maintain the status quo. We also need to challenge social attitudes – especially around the fact that every person should be supported to, and is potentially capable of, making their own decisions with the right support.

'I don't want someone telling me what to do. If it's risky, tell me how to do it safely.'

Person with disability

Damaging assumptions when someone's communication is hard to understand

When we asked another consultation group of people with intellectual disability whether they felt it was okay to change a decision they make, one person answered by showing us their Chicago Bulls cap and shirt. In this context, their response was hard to understand. Did it mean they had changed their mind about which basketball team to follow? Which cap and shirt to wear to the meeting? That they were bored with the questions and wanted to change the topic?

That they had not understood the question?

The consultation format did not allow space for the close communication needed with this person, and likely with people who know them well, to understand whether and how their response connected to the question. But it is critical to understand that when this statement says every person is potentially capable of making their own decisions with the right support, it is referring to everyone.

¹² In 'Supported Decision Making in Disability': Fiala-Butora & Stein, cited by Holler 2022b; Holler & Werner 2022b.

'Chicago Bulls.'

Person with disability

'It's my birthday in September.'

Person with disability

[Crashes props down the stairs to the stage in the hall mid-consult]

Person with disability

The VALID consultant lacked capacity to understand how these ways of communicating connected to the questions asked. But this did not speak to the lack of capacity of people we consulted to communicate their decisions with appropriate support. They spoke to the consultant's limitations in understanding what their communication was trying to tell us. In this way, the consultant's experience mirrored that of some family members and paid supporters: the consultant did not have the time or resources to understand or give genuine effect to the person's communication.

[Speaking out loud to themselves throughout the consultation].

Person with disability

It can be impossible to understand some communication until you spend a lot of time getting to know and understand an individual. But when support, resources and time are allocated to giving every person access to SDM who needs it, their lives get better. Without support to make decisions, people frequently express their frustration and powerlessness through their behaviour. How many 'behaviours of concern' could be reduced or eliminated by meeting their right to SDM?

‘The shift in [legal] supported decision-making from ‘best practice’ to ‘will and preferences’ has been a game changer in my life.’

Person with disability

The support to make decisions like what to wear or where to live is often taken for granted by people without intellectual disability. But this support is often not available to people with intellectual disability. Therefore, it has been assumed they do not have capacity to make decisions. This means many people have never had the opportunity to develop the ability or confidence to make more of their own decisions.

There is not enough data

Another big problem is that existing data on SDM is limited.

VALID-specific data is that about 1 person in every group home we visited during the rollout of the NDIS had no family or independent support for SDM. But further Victorian data that speaks to the usefulness of SDM for people with intellectual disability is limited to 2 small pilots.

Victorian SDM data

Victorian research from the DRC-commissioned research report¹³ that sought SDM data in the context of intellectual disability are the La Trobe ARC Linkage pilot (2016-2020) and the Vic OPA & VALID pilot (2015-2020).

The aim of the La Trobe pilot was to ‘develop innovative education resources, and to then investigate the impact of the resources on the practices of decision-making supporters and the person being supported in a randomised control trial in three jurisdictions (Vic, NSW, QLD).’¹⁴ Participants included ‘55 dyads of a PWIDs and a supporter with an additional five supporters of 4 ppl w high support needs. 27 supporters completed the training and at 25 least one follow up mentoring session. The majority were parental supporters. 27 supporters participated in at least one follow up interview post-training. 21 dyads of people with ABI participated in interviews pre-training but none completed the training.’¹⁵

¹³ Bigby, C. et al., Diversity, dignity, equity and best practice: a framework for supported decision-making, p. 273

¹⁴ Bigby, C. et al., Diversity, dignity, equity and best practice: a framework for supported decision-making, pp. 274-275

¹⁵ Bigby, C. et al., Diversity, dignity, equity and best practice: a framework for supported decision-making, pp. 277-278

The aim of the OPA/VALID pilot was to ‘explore the potential for volunteers to support the decision-making of isolated NDIS participants.’¹⁶ There were ‘15 participants in total (disability not stated). 15 volunteer supporters were matched to the participants.’¹⁷

These are critical pilots that need far more research to validate or refute, and expand on, their findings. There are other pilots that have been conducted outside of Victoria in the context of other cognitive disabilities that may also be informative to a SDM framework for people with intellectual disability in Victoria. But in the meantime, Victoria relies too heavily on guardianship and administration over people with intellectual disability.¹⁸

Guardianship and Administration

From 2016/17 onward, ‘there was a notable and sustained increase in demand for OPA guardianship’¹⁹ with over 900 matters per year. This is in line with VALID’s experience:

‘The guardianship system is overloaded because supported decision making is not recognised.’

Advocate

We will share a case study about Yvie, with her consent, that demonstrates real problems with guardianship and administration. Yvie’s experience shows a common issue that VALID supports people with intellectual disability to navigate around SDM and guardianship.

Content Warning: Coercive support provision

Yvie is a 63-year-old woman with intellectual disability and cerebral palsy. She communicates what she wants clearly yet unconventionally – for example, she gave VALID consent to share her experience here by nodding her head and smiling.

Yvie has a history of institutionalisation, and currently has no informal support.

¹⁶ Bigby, C. et al., Diversity, dignity, equity and best practice: a framework for supported decision-making, p. 274

¹⁷ Bigby, C. et al., Diversity, dignity, equity and best practice: a framework for supported decision-making, p. 277

¹⁸ DRC Final Report – Executive Summary: Our vision for an inclusive Australia and Recommendations, p. 71

¹⁹ Reflections on guardianship: The law and practice in Victoria: <https://www.publicadvocate.vic.gov.au/opa-s-work/research/580-reflections-on-guardianship-the-law-and-practice-in-victoria>

In her current group home, Yvie and others have experienced ongoing issues with the quality of support they receive. Therefore, Yvie was not the only person living in this home to clearly express her wish to change provider.

So people supporting Yvie, including her VALID advocate, got her consent to terminate her support provider's service. When they received this notice, Yvie's support provider applied for guardianship through the Office of the Public Advocate (OPA) to prevent her from terminating their service. This not only worked to deny Yvie's ability to make decisions about things that affect her life, but also to deny her the dignity of risk of potentially making a 'bad' decision. This is despite evidence that showed the service provider had engaged in neglectful professional practices towards Yvie and the people she lived with.

Yvie's service provider claimed they believed that by applying for guardianship through OPA, they could prevent her from making the 'wrong' decision of changing providers.

Issues with rushing into guardianship in this example include:

- A clear conflict of interest when someone's disability support provider makes a guardianship application for them
- Victorian law says that Yvie's guardian would need to do everything they could to make sure her 'will and preferences' (what she wanted) were respected. It would be illegal for anyone to seek a guardianship order in order to stop a person from changing providers. The responsibility of Yvie's guardian would be to learn from Yvie what her decision was, then to help her make that happen
- There was a chance that Yvie's guardian would not have the time, resources or will to learn what she really wanted
- Therefore, Yvie's guardian might make decisions that are not based on what Yvie wants. This might be true regardless of whether their intent was to stop her from changing provider.

'There are support providers who seek guardianship orders so they can make decisions that benefit the support provider.'

Advocate

This example demonstrates real problems for the SDM of unconventional communicators with intellectual disability who have no trusted supporters. One of the biggest problems is that decisions are often made 'for' people instead of 'with' them. Another serious problem is the lack of a clear SDM framework in organisations.

'This lack of SDM framework systematically disempowers and disrespects the rights and self-determination of people with intellectual disability.'

Advocate

This example shows the problem that Yvie had, and it is a problem that often happens for others as well. But a lack of SDM for people with intellectual disability is a problem that does not only harm people with intellectual disability.

Everyone is harmed by a lack of SDM

The problem harms people with intellectual disability. This is because many rarely get the opportunity to learn from the benefits and consequences of their own decisions.

‘How do you know [what] to do if you don’t know about it?’

Person with disability

The problem harms taxpayers. This is because the assumption that people with intellectual disability cannot make their own decisions has led to a resource-intensive, expensive service system.

‘We think people should have 24 hours of staff who do everything for them. They may not need or want that. But that’s the default.’

Advocate

The harm this problem does is substantial, and it can and does go well beyond lost opportunities for people to live lives of their own choosing.

The problem makes life bad for people

SDM is critical to the quality of people’s lives. But VALID cannot avoid discussion about the serious reasons people might argue against SDM for people with intellectual disability.

This case study is an extreme example that demonstrates why it is critical for anyone – but people with intellectual disability in this case – to have several people in their lives who care about them:

Content warning: Incest, child abuse

VALID learned about a woman with intellectual disability who had been sexually abused and assaulted by an immediate family member throughout her life. She didn't know that what was happening to her was wrong. This family member also forced her to have sex with his friends. A guardian was appointed to make sure that he could not see her alone, but she went to see him anyway even though she was sexually assaulted at every visit.

This distressing example might be used to argue that the decision-making of some people is impaired enough that they definitely need guardianship. This argument would show an appropriate amount of fear and concern for a person's welfare.

But VALID does not agree with this argument. We believe this example demonstrates the harm that frequently occurs when people are isolated, segregated, and not supported to make decisions throughout their lives.

How might this story have been different if the woman had independent support when she was younger? Support that could have helped her to understand her relationship with her family member differently? Support to make informed decisions about her response to this abuse much earlier?

Or, if her family member had not been abusive, how might independent SDM have helped this relationship? Helped her to build relationships with people outside her family? To have at least one other person in her life to work through decisions with?

'Because of these kinds of issues, you want to... stop people from making harmful decisions. Understandable... But for her, there was nobody else in her life – which is in many ways the problem.'

Advocate

In situations that are not abusive, the problem still makes life bad for people:

People get no say over the little things in their lives. People get no say over the big things in their lives. People's knowledge of who they are is violated, abused, neglected and exploited by the conscious or unconscious control of others.

'People are robbed of their birthright to express themselves. People's lives happen without them.'

Advocate

Principles

‘It’s never okay to control someone else – it’s best to brainstorm [with them].’

Person with disability

VALID’s SDM principles are grounded in law, policy and research. For about half of 2023, VALID consulted our networks of people with intellectual disability, families, and people and organisations VALID has worked with.

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.

Principle #1: Uphold people’s will, preferences, and rights

‘All other principles flow from this. Education on this principle should create better life outcomes for those in our care.’

Family member

There are different meanings for the words ‘will’ and ‘preferences’. This statement uses the definitions from the La Trobe Support for Decision Making Practice Framework Learning Resource:

A person’s **‘will’** is their **longer term**, enduring sense of what they are trying to achieve. For example, someone’s ‘will’ might be to have more independence.²⁰ (Emphases added)

A person’s **‘preference’** is what they want **right now**. For example, their ‘preference’ might be to move out of home into a unit.²¹ (Emphases added)

²⁰ The La Trobe Support for Decision Making Practice Framework Learning Resource: www.supportfordecisionmakingresource.com.au/will.html

²¹ The La Trobe Support for Decision Making Practice Framework Learning Resource: www.supportfordecisionmakingresource.com.au/preferences.html

'If I'm having a bad day, I'd rather make a decision [that benefits me] now rather than focusing on my goal.'

Person with disability

In the examples above, the person's will (independence) and preferences (move out of home) work well together. But as the quote above shows, this is often not the case – for any of us. This is because, while a person's 'will' might be to have more independence (and therefore they need to save money to move out of home), their 'preference' might be to spend money on things they want right now.

Note-taker in consultation: I used to be a support worker for someone who liked to spend money straight away but was also trying to save money for holidays.
How do you think I should have supported them?

Person with disability: Give guidance on what is going to happen or tell them what will happen if they spend all their money. And if they end up spending all their money, then they learn.

One challenge for supported decision makers is to support a person to understand how their immediate decisions (preferences) affect their longer-term decisions (will). This must be a long-term role supported by people who know the person, like their family members and support workers. This support must also involve at least one independent person trained in SDM who has had time to build a relationship and trust with the person – more if a person communicates in ways called 'behaviours of concern'. There are at least four reasons for this:

1. To safeguard against real or potential abuse.
2. To minimise real or potential conflicts of interest between people with intellectual disability and their formal and informal supports.

'My aunt wanted me to go out with her, but I didn't want to go.'

Person with disability

3. To make sure each person with intellectual disability has as many people in their lives as possible to support them with the different kinds of decisions we all face.
4. To make sure families and staff have the support they need to help create better life outcomes for their loved one / the person they are supporting.

But even when people do everything they can to support a person with intellectual disability to make their own decisions, there are times a supporter cannot figure out the person's 'will' or 'preferences'. This can happen even when they try really hard to understand the person's communication. And there are times they do not have enough information to even justify why the person would choose a given option if they could. When this happens, the person's **rights** take priority.

'When we cannot get a client's instructions, we assume that people want to be safe, housed and supported. These are fundamental human rights.'

Advocate

Neither the advocate nor VALID is saying that a person's 'rights' should ever take priority over their 'will and preferences'. There is a risk of this happening because of a conscious or unconscious lack of effort and/or resources from a person's supporter.

'When this type of decision occurs, it needs to be the exception, and the individual's rights in validating a decision cannot be impinged [upon].'

Family member

Including 'rights' in this principle means there is a risk that a person's rights will be used to justify not taking the time to understand a person's communication – or to avoid the learning and self-reflection needed to work through the fear and uncertainty that comes with supporting someone to make decisions.

'VALID's Keys to Success training helps us to reflect on the fact that we all come with agendas, so we need to be reflective and conscious of the power we have so the person themselves can have their own power.'

Advocate

But 'rights' is an essential safeguarding part of this principle. It should only be used when there is absolutely no way to understand a person's 'will' or 'preferences'.

Principle #2: Safeguards

‘Part of the reason everyone’s a bit worried about people with intellectual disability making their own decisions is they are genuinely at risk because people do target them.’

Advocate

VALID will always advocate for people’s right to support to make their own decisions. What we also know is there are things that can make this support complicated for people with intellectual disability. A major thing is isolation, which can lead to abusive situations between a person and their families or supporters. This is why **adequate human and financial resourcing for supported decision making is a safeguard against isolation.**

‘If you don’t have people that know you, it’s difficult. You need information and a supporter who can balance different ideas with dignity of risk.’

Person with disability

When people are supported to make their own decisions, they are often less frustrated and less likely to communicate their distress through ‘behaviours of concern’ as frequently:

‘If Bill had to live in a group home, he would need a lot of 2:1 staff support. But SDM has been implemented properly with Bill, which means he gets to make choices about what happens in his life. The positive effects of SDM here include reduced anxiety for Bill, and his behaviour reflects a greater sense of calm. Bill and staff are happy, and there are fewer issues than there otherwise would be. This means he only needs 1:1 staff, there is less staff turnover, and therefore fewer shadow shifts. The flow-on effects from these and other differences result in significant cost savings for the government, and a better quality of life for Bill.’

Disability Consultant

This understanding needs to be balanced with information about the person that might put them at an unacceptable risk of harm.

‘Sometimes substitute decision making is necessary. So we need to make sure that practice is as empowering as possible.’

Advocate

For example, a person might need legally appointed substitute decision making support in one or more areas because the risk to their safety or life if they were supported to act on a given decision is unacceptably high.

Consultant: Do you think people supporting you should ever decide something is too risky for you to do?

Person with disability: There are cases where yes or no, depending on what it is.

Because every person and situation are different, ‘dignity of risk’ and ‘duty of care’ are different for every person and situation.

‘[Safeguarding] needs to be done with a person you trust, respectfully, and when denying someone’s rights that they explain it.’

Person with disability

But regardless of the person and situation, the human rights of anyone who may need decision-making support must be respected.

Consultant: Do you ever want people supporting you to make a decision for you?

Person with disability: [First instinct] No! [Upon reflection] ...maybe I'd like it...but no! But... when unwell, I needed it. But the person has to know who I am – have my welfare at heart – be trusted by me. So yes, sometimes, but I'd prefer to make my own decisions.

This often means balancing a person's right to make their own decisions with their right to be safe from immediate danger.

Consultant: Do you think people supporting you should ever decide something is too risky for you to do?

Person with disability: There needs to be an acknowledgment of support needs – but there is risk with all human behaviour. It's a balance.

It is critical to recognise that there are many safeguarding measures that should be taken before the last-resort option of guardianship. These include:

- Funding for peer networks of people with similar experiences to connect with one another
- Mindfulness that supporters should take the least restrictive measures to make sure a person's life is not at risk.

The balancing act with SDM for people with intellectual disability needs careful and ongoing consideration. This consideration needs to happen on a person by person, scenario-by-scenario basis. Tipping too far toward 'will and preferences', under extreme circumstances, can lead to their preventable death. But tipping too far toward making sure a person's 'best interests' are met takes away their choice and control.

'They took the risk away without giving me the choice.'

Person with disability

Principle #3: Minimise conflicts of interest

There is always a power imbalance between a person with intellectual disability who needs decision-making support and the person supporting them.

This power imbalance means the real decisions of people with intellectual disability are not always known. This is inevitable and does not always reflect on the skill or care of the supporter. But knowing that this power imbalance exists means it is especially important to make sure people with intellectual disability have the practical support to make decisions that people closest to them may not like.

Consultant: Do you think it is okay to make decisions that other people don't like?

Person with disability: Yes, because it's about what you want and if it's safe. [The supporter is] there to support you, it doesn't matter what they think.'

'What you think doesn't actually matter – it's not a supporter's role to correct people or try to talk them into something else.'

Former support staff

Paid supporters

We know that many who support people with intellectual disability have their best interests at heart. We also know that many do their best to make sure a person's will, preferences and rights are considered.

But any paid supporter is being paid to be interested in both the person and in the governing rules and interests of the organisation, government agency or family member they are employed by. Therefore, paid supporters have a conflict of interest by definition.

'I want decision making support from someone who doesn't have a stake in the decision.'

Person with disability

This conflict can never be ‘fixed’ by the genuine care the paid person has for the person they’re supporting. That is because this conflict is not about care.

‘Whoever funds and is funded to provide supported decision making needs to be as professionally and personally impartial as possible.’

Advocate

Unpaid supporters

Research says that good families and support staff in a person’s life play an irreplaceable role in supporting them to make decisions. VALID agrees.

‘To ensure them to be able to provide support well, supporters need to have a deep understanding of the person. An understanding of the vision they have for their life, their values and beliefs, goals and priorities, as well as likes and dislikes. The supporter also needs to see the person as an equal human being who they respect.’

Family member

Family members have a critical role in learning what a person’s decision is and supporting them to act on it. At the same time, they too have an inevitable conflict of interest. But unlike with paid supporters, the conflict of interest for an unpaid supporter usually is about genuine care. This is because supporting someone you love to make a decision that might harm them is hard.

Consultant: Do you feel like it is okay to make a decision that other people don’t like?

People with disability: [First instinct] Yes! [Upon reflection] But if it affects others, they need to be involved... but external influences can make the person feel bad about their decision. Like, there’s a reward for making a decision the supporter likes, or bribing, or emotional blackmail. They don’t always know they’re doing it.

‘How can we learn and be equal with everyone else in society if we don’t/can’t learn from mistakes?’

Person with disability

As well as these conflicts of interest, no person without disability relies on just one person for all their decision-making support. So it does not make sense to expect that people with intellectual disability should.

‘Your financial advisor is unlikely to be the person you call on for support when deciding whether to get a divorce or engage in a new hobby.’

Advocate

It is essential that a person has access to independent SDM even when they have family support. This is to minimise the conflict of interest that goes with loving and wanting to protect a family member from harm.

It is also essential to protect people with intellectual disability from more subtle forms of harm. This protection includes working to make sure any decisions that are said to be made by the person being supported, are more likely than not made by them. And that everyone has support to disagree with their parents as adults.

‘Independent support, including peer networks, is necessary alongside existing paid and unpaid support.’

Advocate

Principle #4: Capacity to make decisions must be assumed

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

Person with disability: Assistance to make decisions, but not overly so. You're in control of what you're doing and getting support at the time you need it.

The capacity for people with intellectual disability to make decisions must be assumed. And, in assuming that everyone has the capacity to make decisions, our consultation process highlighted an important consideration:

'There is far too much of those caring for, or representing people with intellectual disabilities saying he or she chose this or that, when there was no evidence the person has the ability to do so.'

Family member

So how can this principle be used to benefit people with intellectual disability and not the interests of people supporting them? What is the benefit of VALID maintaining this principle in cases where there is no concrete evidence that someone has the capacity to make a given decision?

'Capacity is decision specific. A person might be able to make a decision about one thing, but not another. Or they might be able to make a decision about the other thing at a different time.'

Former support staff

We work to make sure this principle is used to benefit people with intellectual disability by minimising real or potential conflicts of interest. To do this, we need to understand that while the

role of support workers and family members is essential in SDM, isolation and lack of access to additional support and information put this principle at risk of misuse. This misuse can be conscious or unconscious.

VALID stands behind this principle because the danger when people are assumed not to have capacity is real: systems, service providers and sometimes families take away people's right to make their own decisions. This is not a risk any of us can afford to take.

'We need to start from the position that every person, without exception, can make decisions. If we believe anything else, then nothing changes.'

Advocate

If it is unclear whether a person has the capacity to make a given decision, it must be assumed they can learn with the right support. They must then be given that support, or support that people close to them and independent supported decision makers have reason to believe might be helpful.

Every effort should be made to support people to make decisions. This includes making sure that people themselves and those supporting them understand what decision a person is making, and how to support this decision well. This is because it is critical that people have their decisions respected and the level of support they need to make them happen in practice.

This also means that **capacity to make a given decision must be assumed regardless of whether someone understands or can act on every step to make the decision happen**. For example, if a person decides to move house but cannot work out a budget without lots of support or at all, it must be assumed they can still decide to move house. That decision must then be respected and genuinely worked towards by the NDIA and other supporters.

'The NDIS need to listen to that, because I'm fighting it because they're not agreeing to what I have said.'

Person with disability

Principle #5: People’s right to make decisions about things that affect them

Consultant: What does making a decision mean to you?

Person with disability: The right to make your own decisions on what can affect your life.

Co-leadership of people with intellectual disability.

Co-leadership of people with cognitive disabilities is Principle 9 of the La Trobe Support for Decision Making Practice Framework Learning Resource, and it is how VALID operates. This is because people with intellectual disability know what they want and need from supported decision making:

Consultant: Do you prefer to make decisions to do what you want now? Or to help you reach your goals?

Person with disability: Someone that brainstorms ideas with you. Write down steps that can help you achieve what you want. Guide you in a certain way, keep a journal, brainstorm with someone, ask people who know you best – ask them what kind of support do you need to reach your goal. I guess search different ways that can help you. Be with you if you think of ideas. Be a ‘buddy’.

People have the right to learn from experience.

Earlier, we talked about how lack of opportunities for people with intellectual disability to have different experiences is one thing that isn’t working. But when people have the right support to learn to make their own decisions, their lives get better:

'I've made a few [mistakes]. I've learned from them, I'm a quick learner.'

Person with disability

'Making decisions means accepting accountability and consequences. If I have to submit documents in 21 days but I decide to take a week longer, [the documents won't be] accepted.'

Person with disability

People have the right to change their minds.

People with intellectual disability, like anyone else, have the right to change their minds. While this can be harder than it needs to be in practice, it is necessary:

'Will my support person be upset if I change my mind? Even though they're meant to not have an opinion or take a side, people do.'

Person with disability

'I changed programs with the group I'm at. It's too easy and I want a challenge.'

Person with disability

People have the right to make decisions others might not agree with.

This is another right that people with intellectual disability have, along with everyone else. Unfortunately, it is also one that can be harder than it needs to be in practice:

Consultant: Do you feel like it is okay to make a decision that other people don't like?

Person with disability: Yes it's okay, but it's scary for people with disability to do something people don't like. It's terrifying to go against society.

But the right to make decisions does not depend on others agreeing with these. While it can be hard to make a decision that goes against what one's family or supporters want, adults with intellectual disability have as much right as anyone else to make unpopular decisions about things that affect them:

'I made the decision to leave my Day Service. I fought for my decision; my decision needs to have freedom attached to it.'

Person with disability

'If [your] parents don't like [a decision you want to make] then try to explain why you want to make the decision and then find someone else to support you somewhere else [if your parents won't support you].'

Person with disability

Because when it comes down to it, SDM is both complex and simple:

Consultant: What does making a decision mean to you?

Person with disability: Being able to be independent, own choice, own voice – it's my right to not agree with someone else.

What people with intellectual disability, their families and advocates have told us

Consultant: What does making a decision mean to you?

Person with disability: Growing up, trying to be independent, doing things for myself.

We asked people with intellectual disability, other disabilities, their families and advocates several questions so we could learn what good and bad SDM looks like in their lives, and whether good SDM is happening for them. Themes that emerged included respecting and responding to the person's communication and humanity.

These are things we all need when making decisions. But they are too often absent in the lives of people with intellectual disability.

What is good support when you need to make a decision?

'I can only speak to those involved in our daughter's care including the family, friends and Support Workers who know her. It is by daily interactions and feedback, mostly nonverbal, that allows us to make informed and supported decisions for our daughter.'

Family member

It does not matter whether a person communicates with their words, body language, behaviour or any other means. Families and independent decision-making supporters need government funding and organisational support – practical and cultural – to take the time to observe and act on people's 'daily interactions and feedback'.

An organisational culture that gives people the space to take risks, make mistakes and learn from these is critical. This not only speaks to respecting the humanity of the person being supported, but also to respecting that of their family members and supporters.

‘People with intellectual disability need to be allowed to make mistakes. Nobody can learn to make the right decisions without making the wrong ones first.’

Advocate

But the most sensible response came from a consultee with intellectual disability. We can talk about themes and styles of communication, and these are important. But ultimately, we need to be open to listening to a person. While we might need additional funding and support to make some decisions happen in practice, something we can all do right away is assume that people have something important to say about their lives and do what we can to work out what that is and how we might support it.

Consultant: What does good supported decision making look like?

Person with disability: When people listen to me.

Having good SDM principles is essential. But if they are not happening in practice, or if they are only happening sometimes, we need to know why. Because it is disrespectful, and in some cases financially unsound, to favour the status quo of not listening to people with intellectual disability over supporting them to make their own decisions.

Are these Principles happening in practice?

Consultant: What support helps you make decisions? What support is good?

Person with disability: Someone you can trust.

When good SDM happens in practice for a person, it shows their communication and humanity are being respected. And SDM is already happening for people, if imperfectly. One advocate sees SDM principles happening in practice in specific situations, at specific times:

‘Where people have families, friendship and preexisting relationships, I see SDM happening. It can be 50/50 in terms of whether they tip into substitute decision making at times.’

Advocate

But the news is not all good. Here is the experience one family member shared when asked whether SDM is happening in practice:

‘Short answer no, I believe we are still operating on the easiest and quickest way to make decisions and that is using our knowledge and making substituted decisions. While we have a lot of knowledge and understanding of our loved ones with cognitive delay, [substitute decision making] is [used] to save time and in some instances frustration.’

Family member

When we asked people what is unhelpful when they need to make a decision, the responses received were both nuanced and simple. Nuanced in that they reflected an understanding of both SDM principles and the complexities of their own additional support needs, and simple in that they reflected what we all want for ourselves: respect for their autonomy and human rights.

What is unhelpful when you need to make a decision?

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

Person with disability: When you say to [a supporter] for example, can I get my driver’s licence? and they say no. Good support says ‘yes, but are you able to do the test?’

VALID learned from people with intellectual disability that there are several unhelpful things a person can do when supporting them to make a decision. But a critical theme that united many responses was disrespect:

‘When people say I can’t make my own decisions.’

‘When people tell me what to do.’

‘When people argue with me or yell at me as if I’m in the wrong. It makes me feel like shit.’

‘Someone who’s patronising or condescending.’

‘Someone who is discouraging rather than encouraging.’

‘Someone who disrespects your decision in front of other people.’

Several issues stand between SDM principles that embed respect, and the practice of these in people’s lives. VALID has been told these include 3 issues:

Why do you think these Principles are not happening in practice?

Consultant: Is it okay to make mistakes and learn from them?

Person with disability: Sometimes yes – if they’re little mistakes, it’s okay. If I made a big mistake, I would be sad.

One issue that stands between SDM principles and practice speaks to the conflict of interest referenced earlier in this paper:

‘There is a tension between the interests of people with intellectual disability and families.’

Person with disability

This conflict / tension is between the natural urge of families to protect their family member with intellectual disability from harm, and their family member wanting to become more independent. This is why VALID is recommending independent decision-making support even for people with intellectual disability who need SDM and already have good, dedicated family members.

Another issue speaks to difficulties in working alongside the NDIA. While the NDIA in this case may be following legislation, it is clear they are not working in the interests of people with intellectual disability:

‘I can support someone with their NDIS goals. I can tell them they are entitled to choose who they live with and who supports them. But the NDIA will not provide that person with all their options. It’s still “if that person themselves does not articulate that they should have those things, push for them, advocate for them, organise around them, fill out the correct paperwork with the correct words by themselves in isolation, they cannot have it.” It’s still a test. That’s unacceptable.’

Advocate

The third issue speaks to problems caused by lifetimes of segregation. This is perhaps the most difficult issue to resolve because the infinite loop of segregation → lack of knowledge → underestimation → justification for segregation can be extremely difficult to break:

‘Many people with disability don’t have experience of what some things mean because of lifetimes of segregation – examples I’ve come across are “advocate” and “marketing”. People around them assume this lack of knowledge is caused by intellectual disability and then underestimate the person.’

Advocate

The next section talks about SDM in the context of existing state and national laws.

What the law says

There are many laws and human rights declarations that clearly articulate people with intellectual disability's right to SDM:

Laws that apply in Victoria

- The *National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No.1) Act 2024* (Cth)
- The *Powers of Attorney Act 2014* (Vic)
- The *Guardianship and Administration Act 2019* (Vic)
- The *Medical Treatment Planning and Decisions Act 2016* (Vic), and
- The *Mental Health Act 2014* (Vic)

Universal Declaration of Human Rights

The Universal Declaration of Human Rights articulates fundamental rights and freedoms for all people:

- **Article 2:** Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind... [this means people with intellectual disability have the same human rights as everyone else]
- **Article 6:** Everyone has the right to recognition everywhere as a person before the law

Australia has signed a legal agreement saying we agree with and will follow what this Declaration says.

The Victorian Charter of Human Rights and Responsibilities Act 2006 (the Charter)

The Charter articulates the basic rights, freedoms and responsibilities of all people in Victoria. It has 20 rights that reflect four basic principles of Freedom, Respect, Equality and Dignity.

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The UNCRPD is an international human rights convention. The UNCRPD articulates the fundamental human rights of people with disability. The human right to make decisions is reinforced in the UNCRPD:

- **Article 3:** ...Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons...

- **Article 4:** ...State Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of their disability...
- **Article 12:** ...safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence...

Australia has signed a legal agreement saying we agree with and will follow what this Convention says.

Victoria's laws and human rights declarations for people with disability are good. But the SDM rights of people with intellectual disability are still often not met.

What the law doesn't say

'So many people have no legal standing when it comes to supported decision making. What should that support look like?'

Advocate

The fact that law now says people with intellectual disability have the right to make their own decisions is groundbreaking. But legal gaps mean that at least 5 realities of people's lives are missed:

1. The lasting impact of inaccurate assumptions

Example: People with intellectual disability have no capacity to make their own decisions.

Historically, this assumption has meant that support was legally based on people's best interests instead of their will, preferences and rights. It will take more than a change of law to stop this assumption from playing out in practice.

2. No resources

There are no independent resources to make supported decision-making happen in practice.

Independent SDM resources are needed in part because many people with intellectual disability have no unpaid support in their lives.

Others have supportive families and workers in their lives. Good families and workers are essential: they have a lasting relationship with the person, they can often understand and interpret complex communication, and they care. Still, independent support in some form is always needed.

3. No standard or framework

There is no formal standard for, or framework around, supported decision-making.

At the time of writing this statement, there is no formal standard or framework for SDM in Victoria.

Any standard or framework that is developed must take into account, and remain flexible in response to, the individual preferences and needs of each person with intellectual disability.

4. Inaccurate and inhumane financial analyses

A simplistic economic analysis shows it is cheaper not to provide support for decision-making.

For example, if 5 people with intellectual disability are supported by 1-2 staff, the cost of support would be less than if each person was supported to make their own decisions every day. This is because SDM would likely lead to an additional 3-4 staff engaged to give effect to people's decisions.

VALID is concerned the NDIA will continue to favour this analysis in practice. This analysis does not consider the potential cost-saving benefits of, for example, supporting people to choose living options that are cheaper than congregate disability housing. It also does not consider reductions in the costs involved in supporting people with 'behaviours of concern' when their need for SDM is met.

Even where these 'simplistic' financial analyses may be correct, they need to be weighed against the serious human rights breaches that happen when people are not supported to live in line with their own values and purpose.

5. Supported decision-making dilemmas compromise support staff

Support workers are not independent supported decision-makers.

SDM that does not come from legal processes is revolutionary in the lives of many with intellectual disability. Support workers are needed to make sure decisions made by people with intellectual disability are supported. But support workers are not independent supported decision makers.

When does Duty of Care become inappropriate Substitute Decision Making?

SDM is complex. One of its complexities happens when an important decision needs to be made but:

- A person has no independent decision-making support
- Support staff cannot work out the will or preferences of the person they are supporting.

'I changed a person's GP when it became clear the GP was not focused on what the person needed. But was I the best person to make that decision? I had no legal authority, but I was the only person in a position to make that call and it was the only sensible option.'

Former support staff

This form of decision-making is often covered by duty of care and the person's rights. But it is frequently used without oversight. This can leave people with intellectual disability vulnerable to their support worker's inevitable conflicts of interest.

Conclusion

There is much that can be said in response to a topic that has been made incredibly layered and complex in good part by false assumptions about the decision-making capacity of people with intellectual disability.

However, given the timing of the release of this Position Statement, we will conclude by saying that genuine and co-designed efforts towards supporting the true decisions of every individual with intellectual disability are critical. Without these, the latest legal and policy consultations and amendments in the disability sector equate to political rhetoric for many.

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 Group²² 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.

²² William Ward-Boas, Gerard Langridge, Sarah Forbes, Naomi Anderson, Kevin Stone, Emily Piggott, Christian Astourian, Katherine Marshall.

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