

**Submission to the
Royal Commission Roundtable into supported decision-
making and guardianship: proposals for reform**

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18 July 2022

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Introduction

This submission responds to the document “*Roundtable: Supported Decision-making and guardianship: proposals for reform*” dated 16 May 2022.

About Us

Villamanta Disability Rights Legal Service Inc (**Villamanta**) is a Victorian state-wide Community Legal Centre (CLC) focused on disability-related legal and justice issues which impact people with intellectual disability. Guardianship and administration are two of our priority issue types; in these matters we act exclusively for the represented or proposed represented person (**PRP**).

Pilot project – duty lawyer for guardianship hearings

In June 2019 Villamanta received a grant from the Department of Health and Human Services under the Disability Advocacy Futures Grants Program. The funded project, “Equal capacity: A project to support changes in guardianship law” had a number of deliverables, one of which was a pilot of a duty lawyer attendance at the Victorian Civil and Administrative Tribunal (**VCAT**).

From August 2019 until March 2020 we provided a duty lawyer service on 38 days of VCAT hearings in five locations (Melbourne, Ballarat, Geelong, Morwell and Shepparton). Across those days:

- There were 313 hearings listed
- 76 PRPs attended in person
- 11 PRPs attended by telephone
- There was a 27.8% attendance rate across all types of attendance

Of those who attended:

- 38 people were represented by our duty lawyer
- 22 had their own legal representation
- 27 did not want representation

We note that these statistics are pre-COVID, and we do not know the impact of VCAT moving to telephone and videoconference hearings has had.

We note that since the change in the guardianship legislation in Victoria, we have not seen a single supportive guardianship or supportive administration order made by VCAT.

Since the commencement of supportive powers of attorney in 2015, we have seen less than five people with such an instrument in place.

Part 1: Supported Decision-Making

We note the use of the term “representative” throughout this section. There is no definition of this role, nor any clarity as to how they would be appointed, by whom, for what purpose or circumstance. Is this similar to a Supportive Power of Attorney? Given the lack of clarity around what is intended, we have found some questions in this section impossible to answer.

Reform Proposal 1: National supported decision-making principles

1) *Do you agree or disagree with the proposed national supported decision-making principles?*

Villamanta broadly agrees with the proposed national supported decision-making principles. We do have concerns about the message behind the prioritisation of Principle 4 (Recognition of the role of informal supporters and advocates) and Principle 5 (Access to support necessary to communicate and participate in decisions).

Prioritising informal supporters over ensuring all people have access to the necessary supports is problematic in our view due to:

- A tendency for some family members to claim a role as an “informal support” that the PRP does not in fact wish them to have; and
- A tendency for the community more broadly to assume all people with disability have family members who can speak on their behalf; and
- The fact that not all PRPs have informal supports or advocates, and they still should be able to access the support they need to maintain and enhance their decision-making capacity.

In our view Principle 5 should be a higher priority than Principle 4.

2) *Are there any unintended consequences or barriers to implementation we need to consider?*

The most significant barrier to implementation of these Principles is the broad lack of understanding about the need for, and nature of the relevant supports. For some people this will also include the imagining, development and funding of supports.

A further barrier to realisation of these Principles arises for those individuals who are without support, and whose isolation causes them to be substantially reliant on service providers. This occurs particularly in closed settings such as group homes, where there is often not a strong culture of respect for decision making rights or the right to dignity of risk.

Reform Proposal 2: Support guideline

1) *Do you agree with the inclusion of the guideline on support?*

The guideline on support does not take into consideration that:

- Service providers will often have a conflict of interest in relation to supported decision making;
- Isolated people who do not know anybody but service providers are often claimed to have “chosen” a support worker or other paid individual to support their decision-making, but this may not be a true choice; and
- It is crucial that all people supporting decision making understand conflict of interest issues, and also that people with disability are supported to broaden their network of people in their lives so as to be able to make real “choices” about their support person.

Reform Proposal 3: Will, preferences and rights guideline

1) *Do you agree with the inclusion of the guideline on will, preferences and rights?*

This section is confusing. Is it about supported decision making or substitute decision making?

Where statements are made about “family members, carers and other significant people in their life” this prioritises family members, which may not always be preferred. Many people with disabilities have had significant conflict with their families, some are estranged, and many adults prefer to rely on friends and peers rather than family members. The statement could easily be made more appropriate by talking about “significant people in their life, such as friends, family members or carers.”

The paragraph about overriding the person’s will and preferences creates a very low threshold and would be open to very broad readings. In our view it should be strengthened to wording such as:

“A representative may override the person’s will and preferences only where absolutely unavoidable to prevent serious and imminent harm.”

Reform Proposal 4: Safeguards guidelines

1) *Do you agree with the inclusion of the guidelines on safeguards?*

This section is confusing. Is it about supported decision making or substitute decision making? The only sentence in this section that makes sense is “Supported decision-making must be free of conflict of interest and undue influence.” The rest appears to be about substitute decision making.

Reform Proposal 5: Decision-making ability guideline

1) *Do you agree with the inclusion of the guideline on decision-making?*

Villamanta broadly agrees with the decision making guideline, but has concerns as follow.

Tendency to apply a higher threshold

In our experience, people with disability have a higher threshold applied to them when it comes to words like “understand the decision and the consequences”.

Our clients have been described as “having the mind of a 5-year old” by those who know them; these attitudes find their way into considerations of whether they can “understand”. Arguments get made about literacy, about understanding complex language, about the details of a decision.

The example we most commonly give is signing a consumer contract such as for a mobile phone or an electricity account. Many people in the community do not read these contracts, but their ability to “understand the decision and the consequences” is not challenged the way it is for people with disability.

Likewise in relation to the issue of the consequences of a decision, arguments get made about our clients’ ability to understand every detail of the outcome of a decision, and all of the possible consequences. People in the community get married all the time, and they cannot possibly know every potential consequence of this decision!

Kind of decisions

It is not clear what is intended by the word “kind” of decision. Examples would assist in clarifying this point.

Changes in decision making capacity

We agree that decision making capacity may evolve or fluctuate, but importantly it can also be developed. It is important to frame this as a learned skill, and not one which just happens.

a. What skills and experience are likely to be required for a person to carry out a decision-making ability test?

The person most commonly asked to conduct such assessments in our experience is a medical doctor. For our client base this is often completely inappropriate because

- They aren't sick.
- The doctor often does not have any idea how the person lives their life, makes their decisions, accesses the community. They only know the medical problems they have had.
- Doctors are often very uneducated in relation to supported decision making, and often have very limited experience of communicating directly with people with disability – there is still an entrenched habit of speaking to the person who attends with them.

Some of the people we have seen provide useful and clear evidence about decision making ability are:

- The person's supporters – those people who see them making decisions in the real world
- The person's allied health team – such as speech pathologists, psychologists and occupational therapists who have worked with them in the community. Fortunately the NDIS has increased the likelihood there will be such professionals who know the person
- People trained in the formal assessment of cognitive functioning (including psychiatrists and neuropsychologists).

b. Should public officials be permitted to undertake this test with appropriate guidance?

It is unclear what is intended by “public official”, nor what relevant skills or knowledge they would have to make such an assessment.

Reform Proposal 6: Recognition of informal supporters guideline

1) Do you agree with the inclusion of a guideline to recognise the role of informal supporters?

While we broadly agree with a guideline to recognise informal support, the wording would need to be very clear so as to differentiate between:

- An informal support that is requested by the person with disability, and a person who simply claims to be an informal support; and
- An informal support for one area of life, and assumptions about involvement in others (for example when parents are relied on for financial decision making, but a first intimate relationship is a topic for peers or siblings only); and
- An informal support that is consciously chosen now, and a habit of many years which is no longer age appropriate; and

- An informal support and an abuser.

a. *What is needed to ensure information protection and prevent potential privacy breaches?*

It is not clear what context this question is contemplating. Government agencies such as Centrelink and the NDIA have nominee arrangements which an individual can agree to which all the informal supports to access information on their behalf, but these arrangements can also be revoked.

The biggest issue with recognising informal supports is the privileging of the voice of the informal supporter over the person being supported. For example, there have been issues where a nominee is appointed by the NDIA, with examples including:

- A seventeen-year old whose mother was the nominee for NDIA purposes, but she had since died. The NDIA would not speak to anybody aside from the mother even after they had been provided with the death certificate. This effectively prevented the participant from engaging with the NDIA in any way.
- An adult whose parents had been appointed nominees due to a guardianship order in place. The participant had the guardianship order revoked, and the NDIA would not revoke the nominee status, providing information about him to his parents against his wishes.

In any arrangement which acknowledges recognition of informal supports, it must be clear that the person has the right to end such arrangements at any time.

2) *Are there any unintended consequences or barriers to implementation we need to consider?*

A risk to consider is that of family violence or abuse. The acknowledgement of informal supporters may lead to the acknowledgement of a person who is mistreating the person being supported and whom they would prefer to have no involvement with their care.

Reform Proposal 7: The right to dignity of risk guideline

1) *Do you agree with the inclusion of a guideline on the right to dignity of risk?*

While we agree broadly that there is merit in including a guideline on the dignity of risk, the statement proposed is problematic.

The statement “the supporter, representative, or organisation need to take a balanced approach to managing risk and respecting a person’s rights” implies these three entities to have the same roles. They do not.

- A supporter does not make decisions for the person, their role is to support.
- A representative needs to mitigate risk only insofar as it is a significant and serious risk.
- An organisation should not be making decisions about management of a person’s risks in any way.

The statement “if a person makes a choice that is possibly harmful to them, then the support, representative or organisation should help the person understand the risk and how it could be managed implies these three entities to have the same roles. They do not.

- A supporter can help the person understand the risk, if the person needs help to understand the risk, and wants this support. This does not mean a supporter can impose their own views of risk on the person. In the community we often see this occur when a person with disability wishes to drink alcohol or smoke cigarettes.

Despite both decisions having proven health risks, many people in the community do these things every day without interference.

- A representative can make certain specific decisions on behalf of a person, and they must make their own assessment of risk. They do not have the right to be interfering in other areas of the person's life and imposing their view of the risks posed.
- An organisation is not generally specially qualified to help a person understand risks, and how they can be managed. Such a proposition should be more carefully articulated, because this is the type of language which leads to coercion and duress.

2) Are there any unintended consequences to consider?

The use of precise language is crucial for this proposal to be of any benefit.

We frequently see service providers limit people's choice because of "insurance". Whose insurance? What does it say? Who does it affect?

Risk is similar. Whose risk is it? Whose job is it to manage that risk? Who decides whether a risk needs to be managed? Who decides if the person understands the risk, or whether they need to discuss it further?

Recently we assisted a client whose finances are managed by State Trustees under a Power of Attorney (ie no administration order is in place). Following a period of persistent conflict with his housing provider, he called State Trustees and asked them to stop paying his residential charge. He acknowledged he would have to pay it at some point, and we explained that he was unable to be evicted for non-payment (there are other orders in place which prevent this). Nonetheless State Trustees refused to withhold these payments, because of "risk of homelessness".

Without precise language, and probably examples, people with disability will continue to have their rights curtailed by others who apply different thresholds of "risk" when there is a disability involved.

For all proposals above

1) What, if any, legal or regulatory effect should the guidelines have?

These guidelines should impose obligations on those entities with significant interaction with people with disabilities, and a disproportionate level of influence over the choices available to them, including:

- Disability service providers; and
- Commonwealth agencies such as NDIA and Centrelink; and
- State based tribunals responsible for hearing guardianship and administration applications; and
- State based systems such as health, child protection, justice, education

The guidelines should form a basis for best practice policy development for the commercial sector in general.

2) Should there be legal duties for public agencies and bodies to secure supported decision-making for people who need it?

Public agencies and bodies should be required to ensure access to supported decision making is in place before they take any other action which curtails individual rights, including:

- Making an application for guardianship or administration;
- Appointing a nominee (without the individual requesting this appointment);

- Restricting the way NDIS funds are managed in a plan, thereby restricting the choice of service providers;
- Making guardianship or administration orders where there has been no attempt at supported decision making;
- Communicating with other parties without consent.

Reform Proposal 11: Safeguard mechanisms

1) *Do you agree that all the Australian, state and territory governments should implement safeguards for supporters and representatives, such as those listed above?*

We agree with safeguards, but are not sure that these are the right ones.

The more effective safeguards are to have more people involved in the person's life, and to have better education around the rights to make decisions.

A simple illustration can be made by the increased number of people requesting assistance with financial abuse matters once the NDIS rolled out. From our experience, these contacts came about because people had access to support workers or support co-ordinators, they had choices about who came into their lives, and built relationships with them. Over time, facts were disclosed that lead these individuals to ask questions, because "something didn't sit right". Prior to having NDIS supports these clients would never have found their way to us.

Disability advocates play an important safeguarding role.

Support providers who get to know their client play an important safeguarding role.

Social networks and community contacts play an important safeguarding role.

Another important safeguard is the availability of funding to:

- Develop the decision making skills of the person with disability; and
- Educate the supporter in their obligations; and
- Educate both parties about the person with disability's rights

2) *Do you consider any of the possible safeguards in the list above to be inappropriate or ineffectual?*

We believe appointment of monitors would be costly and likely ineffective. These arrangements of supported decision making are occurring in homes and daily transactions, it is difficult to see how this can be pro-actively monitored.

The registration of arrangements would potentially be of assistance in identifying opportunists taking advantage of others and abusing these arrangements.

Reporting requirements would be costly and likely ineffective, as well as providing a disincentive for members of the community to provide this type of support.

Police checks are potentially an intrusive and onerous step, given the likelihood of the supporter being a family member. Also, there is the question of who decides relevance in relation to what a police check could potentially reveal.

Part 2: Guardianship

Reform Proposal 15: 'Best practice' safeguards in guardianship

1) *Are the safeguards above the right ones within administration and guardianship? Are any safeguards missing?*

We comment on these proposed safeguards as follows.

Access to alternative dispute resolution would be a useful safeguard where the parties in conflict are not the person with disability. This would include where a service provider, or health system, is in dispute with family members, and makes a guardianship application to override the informal supported decision making.

It is not clear how monitoring would provide an effective safeguard.

Enhanced investigation powers for Public Guardians can provide an important safeguard, but must be resourced appropriately.

The introduction of offence and compensation provisions in legislation are only an effective safeguard if offenders are aware of them.

Independent legal representation and/or disability advocacy should be available for all adults who are the subject of guardianship and administration orders. As noted in the introduction to this document, we saw less than a third of individuals attend VCAT with representation. Of those that did, it is our perception that the majority of those representatives were actually instructed by the family member who was, or sought to be, guardian or administrator. Very few people were represented by an independent person of their own choosing. This would require both funding of representation, and better efforts by tribunals to ensure people are aware this support is available to them.

Our experience of the additional applications for guardianship since the introduction of the NDIA is that this is problematic and needs to be addressed. The reasons, broadly speaking are:

- Misunderstandings about the necessity for a participant to sign a service agreement in order to engage with services. This could be resolved by referral to the NDIS Commission for education.
- The NDIA requiring people with disability to communicate with them as if they did not have the disability. Guardianship applications should never be required to deal with the failures of accessibility of the NDIA.
- Questions around legal capacity and the assertion of rights need to be clarified. For example, if a person has lived in a group home for fifteen years, has indicated to all who know them that they like living there, and they have had their wishes respected with regards to which individuals provide personal supports to them, what happens if their NDIS funding is cut and they can no longer access the same level of support? Should they need a guardian for an application to the AAT, or should it be assumed that they have a right to the funding deemed reasonable and necessary on the available evidence? How is a guardian going to determine what is reasonable and necessary aside from relying on the available evidence?
- State based systems not understanding the NDIS and failing to ensure their clients have access to advocacy support. This would include child protection and justice, where reviews and appeals should have been instigated in relation to underfunded plans, but this simply did not occur.