



Our ref: JC: MLM

NSW Law Reform Commission
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Dear Commissioners,

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Review of the *Guardianship Act 1987*:

IDRS Response to Question Paper 2: Decision-making Models

About the Intellectual Disability Rights Service

The Intellectual Disability Rights Service ('IDRS') is a community legal centre and disability advocacy service that provides legal and other advocacy for people with intellectual disability throughout NSW. IDRS advocates for policy and law reform and undertakes a range of community education with a view to advancing the rights of people with intellectual disability. IDRS also operates the Criminal Justice Support Network ('CJSN') which supports and advocates for people with intellectual disability when they come into contact with the criminal justice system as victims or defendants.

General

IDRS supports supported decision making options wherever possible whilst recognising that substituted decision making may be needed for some people as a last resort.

Drafting legislation about decision making for people with disability is particularly complex because the law attempts to cater for disparate groups of people with a broad range of decision-making incapacities. This includes people whose decision-making incapacity may be temporary, those whose decision-making incapacity may be cyclical, those who may currently lack capacity but have the potential to improve their decision-making capacity and those whose decision-making capacity may be in gradual decline due to conditions such as dementia.

IDRS bases its views on long experience working alongside people with intellectual disability.

The comments made in this submission should be viewed in light of these general statements.

Question 5.1: Formal supported decision-making

(1) Should NSW have a formal supported decision-making model?

IDRS prefers the option of informal supported decision making wherever possible. We support people with decision-making impairments choosing their own decision supporters wherever possible. However, IDRS has a number of concerns about the formalisation of a supported decision-making model.

The potential risks associated with formalisation of supported decision making include:

- discouraging informal supported decision making which can occur naturally and flexibly in a person's everyday life, as experienced by most people
- reduce informal decision support due to a perception that providing decision support without authorisation could entail risk of criticism or liability
- creating a culture where it becomes the norm and the expectation that a person with a decision making impairment must have a formal decision supporter when they make decisions
- that independent decision making may become less recognised and less respected by third parties if the culture develops
- that third parties may be even less willing to recognise informal arrangements
- that formal appointment may suggest fixed general incapacity and work against a starting point of assumed decision specific capacity
- that formal appointments may result in decision supporters with a piece of paper overstepping their role and assuming a substitute decision making role
- formal appointments may reduce flexibility for people with disability to choose a decision supporter at a particular time for a particular decision

It is unclear to IDRS what circumstances would determine the need for a formally appointed decision supporter as opposed to informal decision support.

IDRS proposes that for those who don't have a suitable informal decision supporter in their lives or for those who would prefer independent support for decisions, decision support should be available as a specific service to people when they need it. This should not necessarily require formal appointment.

Any formal supported decision-making model should make clear the role, responsibilities and accountability of supporters.

(2) If there were to be a formal supported decision-making model, how can we ensure there was an appropriate balance between formal and informal arrangements?

There should be legislative recognition of the role of informal supported decision-making arrangements in enhancing a person's decision-making capabilities.

If personal formal appointment of decision supporters is introduced, there should be a requirement that the document appointing the supporter be witnessed by a prescribed witness and include a certificate verifying that the person to be supported appears to understand the nature of the document and its effect. This would allow the prescribed witness to explore with the person to be supported whether informal supported decision-making arrangements might be sufficient.

If tribunal appointments of formal supporters are introduced, the tribunal must be required to first consider whether any informal supported decision-making arrangement would be satisfactory and must only make a formal appointment if no satisfactory informal arrangement can be put in place.

IDRS can see a role for a tribunal dealing with an application for appointment of a guardian or financial manager to adjourn for supported decision making to be attempted in some matters.

Where there is dispute about who should be the person's decision supporter, it would be useful for the Tribunal to be able to appoint a decision supporter.

(3) If there were not to be a formal supported decision-making model, are there any ways we could better recognise or promote informal supported decision-making arrangements in NSW law?

There should be legislative recognition of the role of informal supported decision-making arrangements in enhancing a person's decision-making capabilities.

Lack of access to relevant information, usually due to privacy rules, is an impediment to informal supported decision making. A process is needed by which informal decision supporters can access or assist the person to access information necessary to enable informal supported decision making to occur.

With the introduction of legislative recognition, people with decision-making impairment, families, service providers, public agencies and the general public need to be educated about informal supported decision-making and its benefits. The culture and skills of effective informal decision support should be encouraged and developed through education and the promotion of greater acceptance of the role of informal decision-makers.

Question 5.2: Key features of a formal supported decision-making model

(1) Should NSW have formal supporters?

For the reasons stated in 5.1 (1), IDRS is wary of the introduction of formal supporters.

(2) If so, should NSW permit personal or tribunal appointments, or both?

If personal appointments of formal supporters are introduced, there must be safeguards to ensure that the person to be supported is not unduly influenced when making an appointment. There should be a requirement that the document appointing the supporter be witnessed by a prescribed witness and include a certificate verifying that the person to be supported appears to be aware of the nature of the document and its effect.

IDRS supports the appointment of supported decision-makers by the tribunal but only in specific circumstances where there is a need and where informal supported decision-making is not sufficient for some reason.

The reasons might include that the informal decision support that is occurring is not in the interests of the person with disability or that there is dispute over who should be the decision supporter.

The tribunal may have a role in reviewing personal appointments of a decision supporter if the personal appointment is not working in the interests of the person.

The Tribunal should not be able to appoint a decision supporter if the person is opposed to that appointment.

(3) Should NSW have formal co-decision-makers?

IDRS opposes the introduction of formal co-decision-makers.

The introduction of a co-decision-maker would introduce a new layer of complexity as to questions of capacity and legal liability. IDRS does not see the value of a system of co-decision making. There are dangers that it could easily slip into substitute decision making without the safeguards inherent in formal appointment of guardians and financial managers.

The option of co-decision making shifts power over the ultimate decision away from the person owning the decision. We do not see it as a preferred alternative to supported decision making or to substitute decision making.

(4) If so, should NSW permit personal or tribunal appointments, or both?

IDRS does not support the introduction of formal co-decision-makers.

(5) What arrangements should be made for the registration of appointments?

If formal supported decision-making is introduced, we see difficulties in requiring registration.

Question 5.3: Retaining substitute decision-making as an option

- (1) **If a formal supported decision-making framework was adopted, should substitute decision-making still be available as an option?**

Yes, substitute decision making must continue to be available as an option. IDRS acknowledges that some people are impacted by their disability to the extent that they are unable to make some of their own decisions despite every effort being made to support their decision making.

The incapacity to weigh options and to recognise benefits and risks, leaves some people at risk of, or stuck in, unsafe, unhappy, exploitative situations which require substitute decision making.

- (2) **If so, in what situations should substitute decision-making be available?**

Substitute decision-making should be available as a last resort when a person's incapacity to make necessary decisions is proven and there is a need for a substitute decision maker to protect the person's safety, health, finances or personal and social well-being.

- (3) **Should the legislation specify what factors the court or tribunal should consider before appointing a substitute decision-maker and, if so, what should those factors be?**

The legislation should specify what factors the court or tribunal should consider before appointing a substitute decision-maker. Those factors should include:

- What decisions are necessary
- What supported decision-making options are available and appropriate
- Whether the applicant can show that attempts have been made to put appropriate decision-making supports in place
- Whether any supports that are available or that could reasonably be put in place will be insufficient
- Whether any informal substitute decision-making that has been occurring will be insufficient or is inappropriate in all the circumstances.

Question 5.4: Other issues

Are there any other issues about alternative decision-making models you would like to raise?

Education about informal supported decision making any new alternative formal decision-making models will be needed for people with disability, families, public agencies and service providers.

If formal supporters are to be appointed, training by appropriately accredited providers must be made easily available to those supporters.

Appointment of enduring guardians and attorneys under power of attorney should be widely promoted with easily understood and accessible information so that those who are capable can direct the nature of substitute decision making in their own lives. Information should include safeguards for people to consider when deciding the detail of such appointments.

Question 6.1: When supporters and co-decision-makers can be appointed

General: Supported decision making and co-decision making are very different and the following questions should be considered separately for each.

IDRS does not support formal co-decision making and our comments below relate to supported decision making only.

(1) What requirements should be met before a person needing support can appoint a supporter or co-decision-maker?

If personal appointments of supporters and co-decision-makers are introduced, IDRS considers the person appointing the supporter or co-decision-maker should meet the following criteria:

- Be of or over 18 years of age;
- Understand the nature and effect of the appointment;
- Consider that their decision-making capacity is in question or may be questioned
- Act voluntarily, without undue influence or coercion.

(2) What requirements should be met before a court or tribunal can appoint a supporter or co-decision-maker?

IDRS can see a role for tribunal appointed decision supporters in limited specific situations. For example, when there is dispute about who should be the decision supporter.

A supporter should not be appointed unless the court or tribunal is satisfied that:

- The person to be supported has an impairment to their decision-making capacity;
- The person to be supported could potentially make decisions if the person had support;
- There are no informal arrangements or less restrictive options available to the person to be supported;
- The person to be supported consents to the appointment;
- The proposed supporter consents to the appointment.

Question 6.2: Eligibility criteria for supporters and co-decision-makers

What, if any, eligibility criteria should potential supporters and co-decision-makers be required to meet?

Eligibility criteria that potential supporters should be required to meet are:

- The person is of or above the age of 18 years;
- The person consents to the role;
- The person is able to carry out the role;
- The person is trusted by the person to be supported;
- The person has no conflict of interest with the person to be supported that cannot be satisfactorily managed

Question 6.3: Characteristics that should exclude potential appointees

What, if any, characteristics should exclude particular people from being supporters or co-decision-makers?

Characteristics that should exclude potential appointees include (without limitation):

- The potential appointee has been convicted of an offence involving fraud or domestic violence;
- The potential appointee is employed by an organisation managing a service where the person requiring decision-making assistance lives;
- A court or tribunal has previously decided that the potential appointee should not continue as a supporter;
- Where there is a clear conflict of interest which the potential appointee cannot manage appropriately.

Question 6.4: Number of supporters and co-decision-makers

What limits, if any, should there be on the number of supporters or co-decision-makers that can be appointed?

It is preferable that one formal supporter at any given time should be appointed for financial matters. A person may, however, wish to have different decision supporters for different areas of lifestyle decisions. In everyday life, people choose to get assistance with different decisions from different people. It is important that the person who wants decision support should be able to change their decision supporter over time or as new decisions arise.

If someone has a formal decision supporter, there must be an easy system to change their decision supporter. Informal decision support has an advantage in allowing flexibility for the person to change their supporter without requiring a formal process.

Question 6.5: Public agencies as supporters or co-decision-makers

- (1) **What are the advantages and disadvantages of allowing public agencies to be appointed as supporters or co-decision-makers?**

Our comments refer only to the appointment of decision supporters.

Disadvantages include cost, inadequate resources, impersonality, delays and inaccessibility.

- (2) **In what circumstances, should public agencies be able to act as supporters or co-decision-makers?**

IDRS supports public agencies which are appointed as substitute decision makers, playing a supported decision making role to the extent possible for people who are subject to the agencies substitute decision making.

IDRS believes that the supported decision making role should be primarily available outside public agencies. Appointment of public agencies, whose role is primarily substitute decision making, could create public confusion about the two very different roles.

If an independent decision supporter is needed or if the person does not have someone in their life to play the decision support role, IDRS would prefer that there is a panel of trained independent decision supporters from which the tribunal could appoint someone to take on this role. The role would normally be a time-limited and focused on a particular area of decision making.

IDRS envisages that the panel members would be paid to undertake this role. Supported decision making should not rely primarily on volunteers.

Alternatively, advocacy agencies could be funded to undertake this work as requested or appointed for individuals. IDRS would argue that advocacy agencies already provide decision support to many people on an informal basis.

Question 6.6: Paid workers and organisations as supporters and co-decision-makers

- (1) **What are the advantages and disadvantages of allowing paid care workers to be appointed as either supporters or co-decision-makers?**

IDRS believes that paid care workers should not be eligible to be appointed as a decision supporter through a personal appointment due to potential conflict of interest which the person wanting support may not recognise.

In relation to tribunal appointment of decision supporters, the matter of who should be appointed could be left to the tribunal's discretion provided the tribunal takes account of potential conflict of interest in the relationship.

(2) In what circumstances should paid care workers be appointed as supporters or co-decision-makers?

Please refer to 6.6 (1) above.

(3) What are the advantages and disadvantages of allowing professional organisations to be appointed as either supporters or co-decision-makers?

See answer to 6.6 (4) below

(4) In what circumstances should professional organisations be appointed as supporters or co-decision-makers?

IDRS does not see a role for the appointment of professional organisations as decision supporters.

Question 6.7: Volunteers as supporters and co-decision-makers

(1) What could be the advantages and disadvantages of appointing community volunteers as supporters?

An advantage of appointing community volunteers as supporters could be that it may lead to a personal relationship developing between the supporter and the supported person.

IDRS notes that already existing Citizen Advocacy programs match a person with disability with a community volunteer with the aim of a supportive personal relationship being developed. The Citizen Advocacy relationship will often include informal supported decision making. IDRS is aware of citizen advocates playing highly valuable and effective roles as decision supporters based on their relationship with the person developed through Citizen Advocacy programs.

Any system of volunteer decision support would require allocation of significant resources to train, manage, oversee and support the decision supporters. Thorough recruitment procedures would need to be in place.

A system of supported decision making cannot rely entirely on volunteers to provide decision support for those who do not have anyone in their lives to play this important role.

As previously mentioned IDRS believes that informal decision support should be available as an option for all people with decision making impairments when they need or want it.

(2) What could be the advantages and disadvantages of appointing community volunteers as co-decision-makers?

IDRS does not support the appointment of community volunteers as co-decision-makers.

(3) In what circumstances do you think community volunteers should be appointed as supporters or co-decision-makers?

It may be beneficial to appoint a community volunteer as a supporter for an isolated person who does not have other informal supports, a person who needs advocacy as well as support with decision-making and a person who will benefit from the formation of personal unpaid relationship.

Question 6.8: Powers and functions of supporters

(1) What powers and functions should the law specify for formal supporters?

If formal supported decision-making is introduced, the law should specify:

- That the function of the supporter is to assist the supported person to identify choices, weigh options and to come to a decision.
- Within this role, supporters have powers to assist the supported person to:
 - Access and collect information relevant to a decision to be made by the supported person;
 - Make a decision;
 - Communicate their decision; and
 - Give effect to their decision.

(2) What powers or functions should the law specifically exclude for formal supporters?

The law should include a specific prohibition on a formal supporter acting without the supported person's knowledge and consent.

Question 6.9: Powers and functions of co-decision-makers

- (1) **What powers and functions should the law specify for formal co-decision-makers?**
IDRS does not support the role of co-decision-makers.
- (2) **What powers and functions should the law specifically exclude for formal co-decision-makers?**
IDRS does not support the role of co-decision-makers.

Question 6.10: Duties and responsibilities of supporters and co-decision-makers

- (1) **What duties and responsibilities should the law specify for formal supporters?**
The law should specify the following duties and responsibilities for formal supporters:
- To ascertain the will, preferences and views of the supported person;
 - To work with the supported person to ascertain their will, preferences and views
 - To respect the supported person's right to take risks and make decisions that other people may disagree with;
 - To suggest options which promote the supported person's personal and social well-being;
 - To comply with all legal requirements concerning privacy and confidentiality;
 - To avoid, or satisfactorily manage, conflicts of interest;
 - To not take any action on behalf of the supported person without their prior consent.
- (2) **What duties and responsibilities should the law specify for formal co-decision-makers?**
IDRS does not support the role of a co-decision-maker.
- (3) **What duties and responsibilities should the law specifically exclude for formal supporters and formal co-decision-makers?**
IDRS considers that, if formal supporters and/or formal co-decision-makers are introduced, the law should specifically exclude them from:
- Attempting to obtain information that is not reasonably required for the making of a relevant decision;
 - Using information other than for a relevant decision; and
 - Making unauthorised use or disclosure of information.
 - Interfering with the person's right to seek advice or assistance from a solicitor, advocate or other person of their choosing.

We thank you for the opportunity to make this submission.



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