

NSW DISABILITY NETWORK FORUM

Review of the *Guardianship Act 1987*:

Response to Question Paper 2

31 January 2017

About the NSW Disability Network Forum

The NSW Disability Network Forum comprises non-government, non-provider peak representative, advocacy and information groups whose primary purpose is to promote the interests of people with disability. The aim of the DNF is to build capacity so that the interests of people with disability are advanced through policy and systemic advocacy.

NSW Disability Network Forum Member Organisations:

- Being Mental Health and Wellbeing Consumer Advisory Group
- Blind Citizens NSW
- Deaf Australia NSW
- DeafBlind Association NSW
- Deafness Council (NSW)
- First Peoples Disability Network
- Information on Disability and Education Awareness Services (IDEAS) NSW
- Institute for Family Advocacy
- Intellectual Disability Rights Service
- Multicultural Disability Advocacy Association of NSW
- NSW Council for Intellectual Disability
- NSW Council of Social Service (NCOSS)
- NSW Disability Advocacy Network
- People with Disability Australia
- Physical Disability Council of NSW
- Positive Life NSW
- Side by Side Advocacy Incorporated
- Self Advocacy Sydney
- Synapse (Brain Injury Association NSW)

This submission was developed by NCOSS in consultation with the DNF members and approved by NCOSS Deputy CEO.

Introduction

The DNF welcomes the opportunity to respond to the second Question Paper of the review of the *Guardianship Act 1987 (NSW) (Guardianship Act)*.

Supported decision-making is an important embodiment of substantive equality. It recognises that people with disability are entitled to both:

- autonomy, rights and dignity equal to other citizens; and
- support – if required, to exercise their rights on an equal basis.

Enshrining an entitlement to support allows the law to reflect an empowered view of people with disability.

Supported decision-making marks a fundamental shift from the current paradigm of substitute decision-making. As the DNF noted in our response to Question Paper 1, this review coincides with a period in which many people with disability will have access to greater support than in the past, increasing their life experience and ability to make decisions.

As such, the DNF believes it is important that a wide range of options for supported decision-making should be initially implemented in NSW, accompanied by appropriate safeguards. None of these approaches should be overly prescriptive.

Initially introducing a number of approaches to supported decision-making would ensure support is tailored to the individual and their circumstances. Evidence collected on the operation of the models in NSW as well as other jurisdictions would allow for an evaluation of the circumstances under which

different approaches are effective. Building on the results of this evaluation, the statutory review of the *Guardianship Act* could incorporate evidence-based refinements to supported decision-making. As the DNF argued in its response to Question Paper 1, a three-year statutory review period for the *Guardianship Act* would ensure the Act is responsive to an evolving environment that cannot be fully anticipated.

It is important to remember that supported decision-making is a long-term process. Genuine support to make decisions should occur in personal relationships of trust, where the supporter has a deep knowledge of the will and preferences of the person they are supporting (or an intention to acquire this deep knowledge) and a commitment to maximising the person's quality of life and dignity of risk.

This submission should be read in conjunction with the DNF's response to Question Paper 1.¹

Question 5.1: Formal supported decision-making

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

The DNF believes that a person's right to support for the purposes of decision making should be made explicit in the law with the vehicle or model to facilitate this to be decided according to need. On a theoretical level, legal recognition of supported decision-making would promote an empowered view of people with disability. Practically, legal recognition of the arrangements provides parameters for supporters to act within, providing for guidance and accountability.

Formal recognition would also provide certainty to third parties interacting with the person and their supporter, making it clear that the person that needs support with decisions should be at the centre of all discussions and interactions, and that the supporter's role is secondary.

However, the DNF emphasises that a formal model of supported decision-making should not be overly prescriptive. There are two reasons for this:

- Many people with decision-making impairment need constant low-level support in relation to decisions of daily life, not just major life decisions. (People without decision-making impairment also need support to make decisions, but providing support to a person with decision-making impairment can require specific skills to ensure the person is supported, rather than directed.) Emphasis should be placed on building the capacity of the community to provide support to people with decision-making impairment on this regular basis.
- If the system it is not easy to understand and use, it is likely to be ignored. This would defeat the aims of recognising an individual's right to make decisions about their life and building their capacity to do so.

(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?

¹ [DNF response to review of the *Guardianship Act 1987*: Question Paper 1.](#)

The DNF recognises the importance of maintaining informal support arrangements in a person's life (where these are working well) and supporting a person to develop a network of informal support arrangements.

We support the principle in the Alberta legislation that formal supported decision-making should only be ordered if a Tribunal is satisfied that less intrusive and restrictive measures have been considered and are not likely to be effective.² This could be strengthened by providing a pre-requisite that all other avenues for support have been exhausted.

The legislation should clarify that less intrusive measures include ensuring that a person can access information relevant to a decision in a form appropriate to their circumstances.

(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?

If there were not to be a formal supported decision-making model, the DNF recommends that the *Guardianship Act*:

- state that people have the right to be supported in making decisions;
- recognise the existence of informal supported decision-making networks;
- specifically require informal supported decision-making options to be explored before a substitute decision-maker is appointed; and
- provide that an appointment of a substitute decision-maker must be decision specific.

We support the principle in the *Mental Capacity Act (Northern Ireland) 2016* that substitute decision-making will only be authorised when “all practicable help and support to enable the person to make a decision about the matter have been given without success”.³ We also endorse the steps outlined in the Irish Act as to what constitutes “support to make a decision”. As highlighted in the DNF’s response to Question Paper 1 “support to make a decision” must include the person being provided with information relevant to a decision in a form appropriate to their circumstances.

². *Adult Guardianship and Trusteeship Act 2008* (Alberta) s 13(4)(a)(iii).

³. *Mental Capacity Act (Northern Ireland) 2016* (UK) s 5, s 1(4).

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

Supporters and co-decision makers

As outlined above, the DNF believes that a range of options for supported decision-making should be available, allowing for evidence-based refinements over time. This is the approach recommended by Law Reform Commissions in Victoria and the Australian Capital Territory.

In line with this, we recommend that both supporters and co-decision-makers should be formally recognised, and both personal and Tribunal appointments be permitted.

While personal appointments would best promote the autonomy of the person being supported and ensure a close relationship between the parties, Tribunal appointments should also be introduced as a secondary option. This would allow the Tribunal to consider supported decision-making as a genuine alternative to substitute decision-making, minimising the cases where substitute decision-making is ordered.

We recognise the potential risk of co-decision-makers being appointed if the Tribunal is concerned about the *outcome* of decisions a person would make. To safeguard against this, we recommend that:

- before a co-decision-maker is appointed, the person or Tribunal explores less intrusive and restrictive measures, considering that they are unlikely to be effective; and
- co-decision-makers must inform the Tribunal if they believe they are no longer able to provide the support that the individual may need to make a decision or that the individual no longer requires support to make a particular decision. (as is the case in Ireland) Tribunal appointed co-decision-makers should also be subject to regular review.

Further, the Law Reform Commission should be informed by the functioning and reviews of co-decision models in Northern Ireland and Canada. Particular consideration should be given to

- how these models fulfil Article 12 of the United Nations Convention On the Rights Of Persons with Disabilities (UNCRPD); and
- the extent to which the practice of co-decision-making aligns with legislative intent.

The DNF agrees with the recommendation of the Victorian Law Reform Commission that an appointment of a supporter or co-decision maker by a Tribunal should only be made with the person's consent and the person should be able to revoke the order at any time.

Registration of arrangements

The DNF believes that the requirements for the registration of appointments should depend on whether the supporter is appointed by the person or the Tribunal.

- Registration of personal appointments, or Tribunal appointments of a family member or friend should not be compulsory, as this would over formalise the process.
- Where a Tribunal appoints a supporter who has been external to the person's life, registration may provide a safeguard and accountability measure.

The DNF emphasises that registration of a supporter appointed by the person should carry the same weight as Tribunal appointed registrations.

Question 5.3: Retaining substitute decision-making as an option

If a formal supported decision-making framework is adopted, should substitute decision-making still be available as an option?

If so, in what situations should substitute decision-making be available?

The DNF believes substitute decision-making should be retained as an option of last resort under the *Guardianship Act*.

In our preliminary submission to this review, the DNF argued that substitute decision-makers should be appointed in cases of exploitation where a person is unable to identify breaches of their rights.

Substitute decision-making should also be available where:

- all practicable methods of supporting the person to make a decision, or determining their will and preferences, have been unsuccessful; or
- the timeframe for the decision to be made is such that supported decision-making is not possible, without urgent action the person will be placed at imminent risk.

(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?

It is important for the *Guardianship Act* to emphasise that substitute decision-making is an option of last resort. Including pre-conditions to be satisfied before a substitute decision-maker is appointed is a method of safeguarding a person's autonomy and right to make decisions.

In terms of formulating pre-conditions, the DNF supports the general principle in Northern Ireland's *Mental Capacity Act 2016* that before ordering substitute decision-making, the Tribunal must be satisfied that all practicable help and support to enable the person to make a decision has been given without success.⁴

We also endorse the views of our member, the Intellectual Disability Rights Service, who argues that a substitute decision-maker should only be appointed after:

- actively considering what decisions are necessary;
- actively considering whether supported decision-making options are available and appropriate;
- being satisfied that adequate attempts have been made to put appropriate decision-making supports in place;
- being satisfied that decision-making supports that are available, or could reasonably be put in place, will be insufficient; and

⁴. *Mental Capacity Act (Northern Ireland) 2016* (UK) s 5, s 1(4).

- being satisfied that informal substitute decision-making that has been occurring will be insufficient or is inappropriate in all the circumstances.⁵

The DNF emphasises that the role of the substitute decision makers should be reviewed depending on the decision made, as there may not be the need for that person if circumstances change, or other support becomes available.

Question 5.4: Other issues

Training for supporters

The DNF emphasises that properly resourced guidance of supporters and co-decision-makers is essential if supported decision-making models are to be effective. This has been recognised by the Australian Law Reform Commission.

The process of assisting a person to build their skills, confidence and experiencing in making decisions can be complex, involving a deep knowledge of the person's communication style and their will and preferences. Focuses of the training should include building supporters' skills in:

- using their influence appropriately (rather than effectively becoming a substitute decision-maker) ;
- respecting a person's dignity of risk; and
- building a person's skills, confidence and experience in making various decisions, including by extending their range of experience.

Provision of information about supported decision-making

The DNF emphasises that as part of implementing the revised *Guardianship Act*, community education about supported decision-making should be made available to people with disability. This education would help ensure that people are able to make use of the opportunities the new Act will provide to enhance their skills, confidence and experiencing in making decisions.. The education should be delivered in plain English as well as community languages other than English.

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

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

The DNF believes that there should be minimal pre-requisites to a person appointing a supporter (including a co-decision maker). This ensures the system is not overly complex and maximises the person's autonomy, Further, it emphasises the *entitlement* to support when making decisions outlined in Article 12 of the UNCRPD.

To safeguard against exploitation, it is important that a supporter should not be appointed unless the person needing support understands the nature and effect of the arrangement, and has acted voluntarily, without undue influence or coercion. In circumstances where this is not apparent or is

⁵. Intellectual Disability Rights Service, *Preliminary Submission PGA44*, 3.

contested, the Tribunal could interview the person needing support to ascertain their understanding of the situation. The situation would need to be regularly and formally reviewed.

Requirements should not be phrased to include the words “capable” or “capacity”, as this would undermine the assumption of capacity in Article 12 of the UNCRPD.

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

The DNF believes the following pre-requisites should be satisfied before a Tribunal can appoint a supporter:

- the person needing support or an interested person has applied to the court for an order;
- there is a decision to be made, and an appropriate supporter available;
- the person could make decisions covered by the order if given appropriate guidance and support;
- less intrusive and less restrictive measures have been considered and found unsuitable;
- the order promotes a person’s safety and welfare;
- the proposed supporter or co-decision-maker consents to the appointment, and
- the person needing support consents to the appointment and the order.

To align with the UNCRPD, we believe pre-requisites should not refer to “best interests” or imply a person does not have decision-making capacity. The criteria “there is a decision to be made, and an appropriate supporter available,” stresses that a relationship marked by a commitment to building a person’s capacity is an essential quality of a supporter.

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?

The DNF emphasises two key elements of a supporter’s eligibility; a trusting relationship and minimal conflict of interest. These criteria are crucial because the process of supporting a person to make decisions involves:

- knowing the person including understanding their attributes and style, personal characteristics, likes and dislikes, experiences, skills and level of functioning; and
- identifying and describing the decision, including breaking it into smaller decisions; and
- understanding the person’s will and preference in relation to the decision including by listening to them carefully.

To exercise these skills effectively, a supporter needs an ongoing relationship with the person involving a conscious commitment to set aside their own judgements and inclination to make decisions for the person and/or support a person to develop and act on their will and preferences.

Question 6.3: Characteristics that should exclude potential appointees

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

The DNF believes that a person should be ineligible to be a supporter if the person:

- has been convicted of certain offences;
- works at the facility where the person lives; or
- had acted as a supporter or co-decision-maker for the person but a court has decided they should not continue;

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?

The DNF believes it is preferable for there to be a limited number of supporters and co-decision-makers at any one time given the importance of a genuine relationship of trust between the parties. Where multiple supporters are involved, it is important that there is the capacity for communication to ensure that outcomes for the supported person aligned with their priorities, will and preferences while minimising the risk of unintended consequences.

An individual may access support from different people depending on the type of decision being made and the level of support that they need at that particular time to make that decision. Therefore, it is important to reiterate that the role of a supporter is decision dependent, not ongoing, and can change depending on circumstances.

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

The importance of an ongoing relationship of trust between the parties would make it difficult for officers of public agencies to act as effective supporters or co-decision makers. These barriers may be able to be overcome through specific guidelines or programs allowing public agencies to act as supporters of last resort.

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

The DNF believes issues of conflict of interest must be carefully considered if paid workers and organisations are to act as supporters or co-decision-makers. A person should be precluded from

acting as a supporter if their role exposes them to actual or perceived conflict of interest, or they are in a position of control over the person requiring support.

Applying these principles:

- An employee of an organisation that provides services to the person should be ineligible to act as a supporter, as they may experience pressures from the organisation that make it difficult to act on the person's will and preferences.
- Employees of advocacy organisations would be permitted to act as supporters, in accordance with recommendations of the Victorian Law Reform Commission (subject to the conflict of interest requirements discussed above).

We note that some advocacy organisations may perform services such as support co-ordination under the NDIS. However, as the essence of this service is providing support to build capacity, a conflict of interest is less likely compared to a service provider in the general service system.

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

The DNF believes that community volunteers may be able to be supporters and co-decision-makers provided they are committed to developing an ongoing relationship with the person and a deep knowledge of factors that contribute to the person's will and preferences. Volunteers must receive adequate training and ongoing support in their role in order to perform it effectively.

A volunteer should be appointed where the person needing support has no suitable informal supporters. A volunteer may just be one supporter (or form of support) that an individual might have. As mentioned previously, the type of support required is dependent on the type of decision being made therefore alternative or additional support may be required in different circumstances.

Question 6.8: Powers and functions of supporters

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

The DNF believes supporters should be able to assist people to make decisions related to both personal and financial matters. It is essential that the *Guardianship Act* specify that the function of a supporter is to assist people to access and interpret all necessary information to make a decision themselves rather than make decisions on their behalf.

The ultimate role of a supporter is to assist the person to express their will and preferences. Within this role, supporters should have the power to assist the person to:

- obtain and understand relevant information;
- make and communicate the decisions;
- give effect to the decisions; and
- develop their own skills, confidence and experience in making various decisions including by extending their range of experience.

The DNF believes that supported decision-making orders should specify which of the general powers the supporter can exercise. This is consistent with the obligation to ensure that interferences with a person's autonomy are the least restrictive possible.

The DNF endorses the restrictions on a supporter's use of the supported person's personal information operating in Alberta, namely that a supporter:

- may use and disclose the information only for the purpose of exercising the authority granted to them, and
- is to take reasonable care to ensure the information is kept secure from unauthorised access, use or disclosure.⁶

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

The DNF endorses exclusions to supporters' functions and powers recommended by the Victorian Law Reform Commission that a supporter should be excluded from:

- entering significant financial transactions;
- signing documents that have legal effect;
- making or revoking a person's Will
- managing a person's estate after they die;
- consenting to an unlawful act;
- entering into or ending a marriage or sexual relationship; and
- making decisions about adoption.

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

(1) What powers and functions should the law specify for formal co-decision-makers?

In performing their ultimate function of making decisions jointly with a supported person, the DNF believes co-decision-makers should have the following powers and functions:

- ability to access or obtain information relevant to a decision;
- discuss the information with the supported person, including the known alternatives and likely outcomes of the decision;
- assist the person make a decision, including determining their will and preference; and
- do everything necessary to give effect to the decision.

The DNF endorses the recommendations of the Victorian Law Reform Commission that co-decision-makers should be able to assist with both personal and financial decisions, but that particular powers and their limits be specified in the individual order. This approach strikes an appropriate balance between flexibility and safeguards.

As a further safeguard, we recommend adopting the requirement in Irish legislation that a co-decision-maker inform the Tribunal if they believe they are no longer able to provide the support that the

⁶. *Adult Guardianship and Trusteeship Act 2008* (Alberta) s 9(3).

individual may need to make a decision or that the individual no longer requires support to make a particular decision. Tribunal appointed co-decision-makers should also be subject to regular review.

(2) What powers and functions should the law specifically exclude for formal co-decision-makers?

The DNF believes co-decision-makers should be excluded from performing the following functions:

- making decisions on behalf of the supported person or without their consent;
- signing legal documents relating to the supported person without a co-signature from the supported person;
- making or revoking a person's Will;
- managing a person's estate after they die;
- consenting to an unlawful act;
- entering into or ending a marriage or sexual relationship; and
- making decisions about adoption.

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 DNF believes that supporters should have a duty to:

- reflect a person's will and preference; and
- assist a person to build their skills confidence and experience in making various decisions, including by extending their range of experience.

(2) What duties and responsibilities should the law specify for formal co-decision-makers?

The DNF believes that co-decision-makers should have a duty to:

- reflect a person's will and preference; and
- assist a person to build their skills confidence and experience in making various decisions, including by extending their range of experience.

In addition, both supporters and co-decision makers should consider general principles built on those put forward by the Victorian Law Reform Commission and the Australian Law Reform Commission:

- The wishes and preferences of all people should inform decisions made in their lives. This includes people who require different levels and types of support to make decisions.
- People who require support to make a decision are entitled to take reasonable risks and make choices that other people might disagree with.
- Any limitations on the rights and freedoms of a person who requires support to make their own decisions must be justified, reasonable and proportionate.
- People may choose not to be supported.

- The capacity of the support available to the person should be assessed, not the person themselves, or the possible outcomes of their decisions.

(3) What duties and responsibilities should the law specifically exclude for formal supporters and formal co-decision-makers?

The DNF endorses the exclusions identified in Ireland, namely that “interventions” must, among other things, “have due regard to the need to respect the right of the relevant person to dignity, bodily integrity, privacy, autonomy and control over his or her financial affairs and property”. The guiding principles also provide that an “intervener”:

- shall not attempt to obtain information that is not reasonably required for making a relevant decision;
- shall not use information other than for a relevant decision; and
- shall take reasonable steps to ensure that information is kept secure from unauthorised access, use or disclosure and is safely disposed of when he or she believes it is no longer required.⁷

⁷. *Assisted Decision-Making (Capacity) Act 2015* (Ireland) s 8(6)(b), s 8(10).