



Justice
Public Guardian

NSW Law Reform Commission Review of the
NSW Guardianship Act 1987
Question Paper 2: Decision Making Models

Submission February 2017

NSW Public Guardian

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Mr Alan Cameron

Chairperson

NSW Law Reform Commission

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Dear Mr Cameron

The Office of the Public Guardian is pleased to be able to participate in the review of the NSW Guardianship Act.

We welcome the opportunity to respond to the Law Reform Commission papers and to play an active part in the consultation process.

Please see attached our submissions in response to Question Papers Number 2 and 3.

Kind regards

A handwritten signature in black ink, appearing to read 'Graeme Smith', written in a cursive style.

Graeme Smith

PUBLIC GUARDIAN

Introduction

The Office of the Public Guardian (the Public Guardian) believes it is appropriate to review the Guardianship Act at this time as it has been in operation for more than 25 years and much has changed over the past 25 years for people with disabilities in both our domestic law and in the international law.

Since 2008 a primary reference point when considering the rights of people with disabilities has been the United Nations Convention on the Rights of People with Disabilities (UNCRPD). The Public Guardian believes that the aspirations contained in the Convention should be the starting point when embarking on a process of reform of any legislation that relates to people with disabilities.

The National policy setting for people with disabilities in Australia is characterized by an emphasis on choice and control over the services they receive and who provides them.

The Public Guardian believes that people with disabilities should not be stripped of their legal personhood by the State when their ability to make decisions, to exercise choice and control, is limited or impaired. Instead they should have access to the support they need to assist them to make their own decisions. Sometimes the nature and the level of this support will be extensive.

At least until supported decision making is well established in the community access to fully supported (substitute) decision making may be required in a limited number of cases.

The Public Guardian has been involved in the developing field of supported decision making for several years. We have partnered with NSW Trustee and Guardian and NSW Family and Community Services in two supported decision making projects; one of these is continuing and is managed by this office. We have developed our decision making guideline for staff to be more explicit about the importance of establishing and following as far as possible the will and preferences of the represented person. We provide administrative support to the Australian Supported Decision Making Network.

Our experience in the field of supported decision making so far indicates that:

- Decision making support happens in communities that see people with cognitive disability as decision makers. So much depends on the good will and active support of the people around the individual.
- Support for decision making takes time and facilitation of a supportive relationship that involves challenging the supporter's assumptions. Many organisations aim to operate from a supported decision making paradigm but have not yet developed policies and procedures that support this approach. This leads us to believe that supported decision making is in its infancy.
- Further, there is no existing infrastructure from which people with disabilities can access decision making support and this will need to be developed through education and funding support by both levels of government. Ideally people will access support from family and friends. This however, will not always be possible and so a network of support agencies will be needed.

Question 5.1: Formal supported decision-making

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

Question 5.3: Retaining substitute decision-making as an option

Question 6.8: Powers and functions of supporters

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

The Public Guardian is appointed to act for a diverse group of individuals who have one thing in common: decision making impairment. However, the level of impairment, its impact, and the level of the person's engagement in their community are all very different. Our current system of guardianship operates from a binary model – a person either has legal capacity or crosses a line to become a person with 'no capacity to make certain decisions' and therefore to lose legal capacity. The Law Reform Commission's review invites us to consider a fundamental change to the standard account of capacity and decision making, to challenge existing assumptions and begin looking at ways to evaluate the level of support needed to assist a person to make or participate in decision making to the greatest extent possible, rather than to continue focus on whether a person does or does not 'have capacity'.

The Public Guardian believes that our community is not yet ready to offer sufficient support and safeguards to people with decision making impairment that might allow for the removal of substitute decision making; that there is a continued need for some form of guardianship, but the form it takes is very much ready for review and amendment.

While the standard system of guardianship operates from a binary model, this office's experience is that the Guardianship Division of NSW Civil and Administrative Tribunal, formerly the Guardianship Tribunal and previously the Guardianship Board, treats each hearing as a separate event, focusses on the needs of the person subject to the application and on the whole, creates an order based on evidence of their needs and with the least restriction. The Public Guardian's office, as far as possible, makes decisions that promote the wishes and interests of the person under guardianship. The general principles of the NSW Guardianship Act ('the Act') help avoid a prescriptive approach by allowing the Guardianship Division and guardians the flexibility to respond to the person individually and consider various areas that impact decision making – protection, independence, social connections and personal views.

The best practice of guardianship clearly and effectively promotes the interests of represented people. This office is confident that our intervention regularly results in positive outcomes for individuals with decision making impairment, outcomes that may otherwise never have been achieved. But the cost of guardianship is the individual's legal capacity and an ongoing community expectation that guardianship is required for people with disability. Therefore this office is supportive of new laws that could offer different types of decision making support and move away from a dependence on the concept of capacity towards a measurement of a person's support needs.

The Public Guardian is supportive of a formal supported decision making model as well as increased support of the existing informal system of decision making support in the community.

OPG envisages a formal system that started with identifying the level of support a person needs in order to participate in decision making as fully as possible. A focus on 'capacity

assessment' often confuses issues of legal capacity with mental capacity. Along a spectrum of support, rather than of capacity assessment, a person may need a small amount of assistance, such as information gathering and ordering, to a higher level of support to actively create and investigate options, to perhaps shared decision making. A minority of people will require a high degree to support such as guardianship, if they are unable to participate to the extent necessary for significant decisions to be made.

The Australian Law Reform Commission's decision making principles, outlined in the report of their inquiry into Equality, Capacity in Commonwealth laws offer a solid framework for the establishment of support decision making in Australia:

Australian Law Reform Commission: decision making principles

Principle 1: The equal right to make decisions

All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

Principle 2: Support

Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

Principle 3: Will, preferences and rights

The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

Principle 4: Safeguards

Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

New models of decision making support

Changes to the Act could include a range of tools along a spectrum of support:

- **Informal support** between individuals does not need regulation in the Act, but could be acknowledged and reinforced by it. Expanded principles could apply to all relationships of support to offer guidance to decision makers and supporters about good practice.

Most people with disability are, like the rest of the community, unlikely to need a formal system of decision making support. The importance of the role of advocacy, including peer advocacy could be acknowledged as an effective source of accessible and effective support. In some situations the person responsible hierarchy in section 33A of the Act could be useful in offering guidance about who could support a person to make decisions.

- **Supported decision making agreements** or authorisations could be described within the Act to offer guidance to decision makers and their chosen supporters. Supporters would not have decision making authority. Agreements could be witnessed or registered to offer some oversight. They might be used
 - by people who don't have informal supports in their lives
 - to allow greater 'proof' of the supporter's role, for example when seeking information from financial institutions

- by people who want to formalise their relationships of support, for example to reinforce their identity as a decision maker and to define the limits on others who may wish to make substitute decisions for them.

When appointed, the Public Guardian often works largely as an advocate to identify and engage resources so that the decision the person prefers can be made. In our current guardianship system the guardian retains decision making authority over the person, regardless of whether the decision is largely or completely the person's own decision. In a supported decision making agreement the person would retain their decision making rights. The supporter's role may be significant in representing and advocating for the person's preferences and choices, but the supporter would not be able to make substitute decision.

There may be a role for a public authority such as a Public Advocate to act as a supporter in a supported decision making agreement or to offer facilitation and oversight of the role. The possible role of volunteer supporters is discussed later in this submission.

- **Co-decision making agreements** might act as a stepping stone away from guardianship. The Public Guardian acknowledges the challenges of this model but believes it could offer a useful alternative view point on the standard system of substitute decision making. NCAT could create co-decision making agreements in place of guardianship orders to acknowledge the person's ability to participate in decision making. They could be used in circumstances where a person's decision making support needs increase beyond a supportive arrangement, to the point where they are not able to make a specific decision or are not able to make the decision within the timeframe available, for example in a situation of crisis accommodation.

A co-decision making agreement might work for a person who is sometimes unable to engage in decision making and the consequences of this inability have significant impact on their quality of life or ability to live according to their wishes and preferences. Most people will decline to or feel unable to make decisions from time to time and a co-decision making agreement would not be appropriate where a person simply chooses not to make a decision, but it might be needed where the impact of the person's inability to participate in decisions creates significantly negative outcomes for them. For example, a co-decision making order might work for someone who, after exhaustive attempts cannot be supported to make their own decisions about where they live or the treatment they are prescribed and without a co-decision a decision could not be made, causing them harm.

In many cases the person would still be able to direct decision making. The co-decision maker would be responsible for seeking opportunities for the person to develop their capacity to participate in decision making. When making decisions the co-decision maker would be bound by the principles of the Act.

For most people, decision making doesn't happen in isolation and autonomy is often achieved through give and take, through relationships of trust and through skills that have been acquired over time - capacity building. For people with cognitive

impairment in particular, the concept of shared autonomy may make autonomy accessible. Solo decision making may be a difficult goal and shared autonomy may be more appreciative of the person's support needs, their individual circumstances.

- **Guardianship orders** could remain an option for the minority of people who cannot participate in decision making without significant interpretation by others of their views, will and preferences. The Public Guardian favours a move away from the terminology of 'guardianship orders'. Alternative terms, even such as the Canadian term 'conscientious representation' encourage the substitute decision maker to see their role through the prism of responsibility to represent the person and to do so with deep understanding of the person, rather than a best interests approach.

Representative orders could be adapted to include greater direction to guardians about making decisions based as far as possible on the person's will and preferences. Again, the Australian Law Reform Commissions' principles offer a useful structure.

Australian Law Reform Commission: Recommendation 3–3 Will, Preferences and Rights Guidelines

(2) Representative decision-making

Where a representative is appointed to make decisions for a person who requires decision-making support:

- (a) The person's will and preferences must be given effect.
- (b) Where the person's current will and preferences cannot be determined, the representative must give effect to what the person would likely want, based on all the information available, including by consulting with family members, carers and other significant people in their life.
- (c) If it is not possible to determine what the person would likely want, the representative must act to promote and uphold the person's human rights and act in the way least restrictive of those rights.
- (d) A representative may override the person's will and preferences only where necessary to prevent harm.

Four levels of decision making support may seem expansive in comparison with the existing system, but a range of options creates a realistic response to the different support needs experienced by people with cognitive impairment. It's possible that this submission's classification of 'co-decision making' and 'representation orders' could be blended into a single tool, using the same goals and principles.

Safeguards

The Public Guardian appreciates that concern about risk is usually the first response to any discussion about alternatives to guardianship. This office recognises and shares concerns over the risks described within the Question Paper but believes concern about risk should not prevent people with disability from claiming greater control over their decision making and their right to legal capacity.

Safeguarding measures should promote the social, financial and personal wellbeing of the person to enable their greater participation in decision making, not to close the person off from the dignity of risk and opportunity based on generalised concerns and assumptions about their disability.

The Public Guardian is supportive of the Australian Law Reform Commission's recommendations as a general guide to limitations of supporter and decision making roles.

Australian Law Reform Commission: Recommendation 3–4 Safeguards Guidelines

(1) General

Safeguards should ensure that interventions for persons who require decision-making support are:

- (a) the least restrictive of the person's human rights;
- (b) subject to appeal; and
- (c) subject to regular, independent and impartial monitoring and review.

(2) Support in decision-making

- (a) Support in decision-making must be free of conflict of interest and undue influence.
- (b) Any appointment of a representative decision-maker should be:
 - (i) a last resort and not an alternative to appropriate support;
 - (ii) limited in scope, proportionate, and apply for the shortest time possible; and
 - (iii) subject to review.

More specific safeguards would be needed, for example to ensure that co-decision making agreements were created for people with significant decision making support needs, not simply for people in need of advocacy that could be provided for by other means, such as informally in the community. The Public Guardian is supportive of limits and exclusions being placed on co-decision makers, such as those described discussed within the Question Paper.

The Public Guardian has a Private Guardian Support Unit which could be used for supervision, training and awareness-raising of supporters and co-decision makers, as well as guardians/representatives. These services may be more effectively delivered through a Public Advocate. A Public Advocate could have a regulatory or investigatory role with supporters, co-decision makers and representatives. The Public Guardian anticipates there will be scope to discuss the role of a Public Advocate in the next Question Paper from the Commission.

- **Principles**

The principles of the Act are fundamental to safe decision making and safe processes. The Public Guardian discusses the principles of the Act in Question Paper 3.

- **Staged commencement: testing the hypothesis**

While various forms of support of course occur every day, an intentional and structured system of decision making support is in its infancy in Australian and internationally. As the Question Paper points out, there is limited evidence of the value and impact of different types of supported decision making models. The Public Guardian advocates introducing changes to the legislation through staged commencement with legislated review provisions, to allow time and space to test whether the changes do in fact deliver greater legal agency to decision makers or whether there are negative and perhaps unintended consequences.

- **Community education**

Community education will be critical to the introduction of any new system of decision making support or other changes to this long standing legislation. The Public Guardian's responsibility to give information to the community about the role and function of

guardianship could be expanded to include a responsibility to provide information about other forms of support. The Public Guardian has produced and is currently delivering a NSW-wide supported decision making training package through the Supported Decision Making Project.

Education and awareness-raising would provide

- Information for decision makers, supporters, service providers, facilitators (including coordinators of support), families, enduring guardians and other substitute decision makers about the principles, safeguards and best practice of the decision making model(s).
- Training about the principles and 'how to' of support and decision making
- Advice and mentoring about supported decision making practices, including the promotion of a framework and best practice.
- Individual and systemic advocacy.
- Development of resources.

Concerns about misuse of decision making tools or concerns for the support needs of a person could be referred for investigation if the office held investigatory powers.

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

The first NSW supported decision making project, between Family and Community Services, NSW Trustee and Guardian and NSW Public Guardian, indicated that many people with disability found it difficult to identify supporters. Project participants sometimes chose workers because they didn't have family supports; sometimes they didn't want their family to support them and sometimes their families or friends didn't want to take on the role of supporter. A robust system of support options, whether paid or unpaid will need to underpin a model of supported decision making, and to acknowledge that decision making support is time and resource intensive.

The current NSW supported decision making project, led by the Public Guardian and the previous project indicate a role for facilitation that may need to sit with a public agency, in the absence of any private or non-government agency being able to take on the role. Comment is made on this issue in Question Paper 3.

As the success of co-decision making is dependent on the quality of the relationship between the person and their supporter, appointments based on the person's choices should be followed wherever possible. Appointments not led by the person's choices should only be made with clear evidence that the person's preferred supporter was excluded by legislation – for example that they did not want to take on the role, they were not committed to supporting the person to make their own decisions or had a significant conflict of interest.

If co-decision making was to replace guardianship orders in some cases there may be a need for the Public Guardian to remain the appointee of last resort.

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

Decision making support should be a normal part of any service delivery. In a formalised relationship of support or co-decision making, paid relationships can create a power imbalance, conflict of interest or situation of undue influence. Some paid workers may have a low level of interest in and knowledge of the person.

However, some paid workers may offer a rich source of support to people with limited social connections. For example a person living in a group home without family or close friends may feel closest to paid support workers who they see every day. One participant in the Public Guardian Submission to NSWLRC Guardianship Review Question Paper 2

current Supported Decision Making Project told the Public Guardian that they didn't have someone in their life who they wanted to support them, nor did they want to work with a volunteer supporter. In their view, a paid relationship offered clarity of roles and expectations – they didn't want to have to be 'friends' with a volunteer, they wanted a businesslike transaction of support and outcomes.

The Public Guardian suggests the Act should seek to promote a person's legal capacity and agency, not seek to control who a person with disability goes to for support. While serious attention must be given to safeguards within the act, in general a person should be able to choose who they want to seek support from, and to choose to create a formal supported decision making agreement. At the level of co-decision making higher standards are required, as they involve the appointment of a supporter who would potentially make substitute decisions.

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

While the person in the example above didn't wish to engage with a volunteer, other people may wish to. Community volunteers offering fast, accessible and flexible support may be an effective way to grow community acceptance of people with cognitive disability as decision makers. A successful volunteer system with community development benefits will need the support of training and oversight or supervision. As in other states, such as Victoria, a Public Advocate could provide oversight, administration and support of a successful community volunteer system. Again, community advocacy organisations, including those offering peer advocacy, should be acknowledged as an important existing source of decision making support.