



Royal Commission
into Violence, Abuse, Neglect and Exploitation
of People with Disability

Supported decision-making and guardianship: **proposals for reform**

16 May 2022

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Introduction

Our inquiry

The Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) is looking at the right to autonomy for people with disability, including how this applies in guardianship and decision-making arrangements.

Our terms of reference direct the Royal Commission to inquire into:

what should be done to promote a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation¹

what governments, institutions and the community should do to prevent, and better protect, people with disability from experiencing violence, abuse, neglect and exploitation, having regard to the extent of violence, abuse, neglect and exploitation experienced by people with disability in all settings and contexts.²

The terms of reference also require us to consider the critical role families, carers, advocates, the workforce and others play in providing care and support to people with disability.³

Purpose of the roundtables

The Royal Commission is holding two policy roundtables to hear feedback on proposed reform directions for supported decision-making and guardianship in Australia. These concepts are defined in the **Appendix**, along with other key concepts.

The proposed reform directions are based on the work we have done to date and the requirement in our Terms of Reference to consider the findings and recommendations of previous relevant reports and inquiries.

Supported decision-making roundtable

The first roundtable will discuss how a national policy and legislative framework for supported decision-making can be implemented as an alternative or complementary approach to substitute decision-making for people with disability. The proposed national framework sets out principles and a model for how these principles should be applied in different contexts, including guardianship and administration, the National Disability Insurance Scheme (NDIS), health care, supported accommodation, and the criminal justice system.

This roundtable will focus on the proposals for reform in **Part 1** of this paper.

Guardianship and administration roundtable

The second roundtable will examine proposals for how a national supported decision-making framework can apply within the context of guardianship and administrative systems in Australia.

This roundtable will focus on the proposals for reform in **Part 2** of this paper. Part 1 provides important background to the proposed options outlined in Part 2, and the two parts should be read together.

Human rights basis

Our terms of reference recognise the human rights of people with disability, including ‘respect for their inherent dignity and individual autonomy’.⁴ This Royal Commission seeks to translate those rights into practical and sustainable policies and practices, to reflect the values and standards the community expects to be upheld for people with disability.⁵

Historically, many people with disability have not been allowed to make decisions and take risks in their own lives.⁶ In its preamble, the *Convention on the Rights of Persons with Disabilities (CRPD)* recognises the importance of autonomy for people with disability.⁷ The first general principle in article 3 of the *CRPD* is:

Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons.⁸

Article 12 of the *CRPD* is ‘Equal recognition before the law’. Article 12 also recognises that people with disability may require support to exercise their legal capacity.⁹ Guidance on the *CRPD* advises that, according to article 12, a person cannot lose their legal capacity to act because of disability.¹⁰ The CRPD Committee describes support as ‘a broad term that encompasses both informal and formal support arrangements, of varying types and intensity’.¹¹

Although article 12 does not explicitly prohibit substitute decision-making, the CRPD Committee has said compliance with article 12 requires elimination of such regimes and the development of alternatives.¹² The Committee has also said that having supported and substitute decision-making systems in parallel does not comply with article 12.¹³

Despite this guidance, different perspectives remain around the interpretation of article 12, including whether legal capacity can be overridden, and when and whether substitute decision-making is allowable.¹⁴ During the drafting of the General Comment for article 12, the Australian Government outlined its concerns that, while it recognises the importance of respecting the legal capacity of people with disability ‘to the fullest extent possible’, there are situations in which ‘substituted decision-making may be the only available option’.¹⁵

What we have heard about decision-making and guardianship arrangements

The Royal Commission has held 13 Public hearings to date that have raised these issues.¹⁶ Witnesses have given evidence that supported decision-making provides greater opportunities for people with disability to exercise their autonomy.¹⁷ A further hearing on guardianship and administration, to be held from 21-25 November 2022, will build on these policy roundtables and previous hearings. It will provide an opportunity for people with disability to give evidence about their lived experience of guardianship.

As at 6 May 2022, the Royal Commission had received 1,230 submissions and held 333 private sessions that have raised issues about guardianship, choice and control, and decision-making.

People with disability have told the Royal Commission about the ways their autonomy is limited or denied. People have described how options are not available to them or decisions are made for them, so they feel unable to lead their own lives. We have heard about a lack of autonomy in decision-making related to education, work, living arrangements, relationships, sex, and access to services, including the NDIS. We have also heard about everyday choices, such as when to get up and what to eat, being limited. Some people have described substitute decision-making in connection with experiences of violence, abuse, neglect and exploitation.

Substitute decision-making can also occur formally, including under guardianship and administration orders. We have received 133 responses to issues papers that have covered guardianship and administration. These responses have mainly been to the *Rights and attitudes*, *Promoting inclusion*, and *Safeguards and quality* issues papers.

Guardianship and administration orders are intended to be a safeguard against violence, abuse, neglect and exploitation. The Royal Commission has heard that, while guardianship and administration serve this purpose for some people, for others they limit decision-making and autonomy. This can have detrimental impacts across multiple areas of their lives. We have also been told that it can be difficult to navigate these systems and access complaint mechanisms, and that they lack regulation and accountability. We have been told that these systems disproportionately affect people with disability, and can have significant impacts on those subject to them.

Some people have described Public Guardians or Trustees mishandling funds or acting in a way that led to a decline in a person's wellbeing and standard of living. We have also heard about people with disability being financially exploited by family members who have guardianship or administration over them.

We have also been told that, despite legislative requirements, guardianship and administration orders are often not used as a last resort. We have heard concerns about the increasing use of guardianship as a means of obtaining authorisation for the use of restrictive practices.

The key themes across evidence and information gathered by this Royal Commission are explained below.

Violence, abuse, neglect and exploitation under guardianship and administration orders

Some submissions assert that the actions of a Public Guardian or Trustee have led to a decline in a person's standard of living or adverse life course outcomes, such as the loss of housing or accommodation.¹⁸ Others have described a lack of choice over living arrangements and their finances,¹⁹ and the lack of opportunities to develop skills such as financial literacy.²⁰

Guardianship can be a safeguard

Public hearings held to date provide examples of when guardianship and decision-making arrangements have been a safeguard, particularly when advocates have applied for guardianship. In these circumstances, guardians can be a source of support and protection against violence, abuse, neglect or exploitation for people with disability living in closed institutions.²¹

In Public hearing 11, the guardians for Winmartie and Melanie brought their respective cases to the Royal Commission's attention. These guardians have strongly advocated for improved conditions and reduced use of restrictive practices. In this context, the role of guardianship has provided a degree of scrutiny and accountability. In evidence given to the Royal Commission, these guardians centred their role on the wishes and preferences of the person they represent.²²

Balancing duty of care and dignity of risk

The Royal Commission has been told that 'having choice in our lives involves risk'.²³ We have also heard that there is no one in the community who behaves in a way that doesn't involve risk.²⁴ The importance of balancing duty of care and supporting a person's dignity of risk has been examined in public hearings.

Stakeholders have told the Royal Commission that service providers may restrict the lives of people with disability because of fear that they do not have a good understanding of risk, and that the service providers will be held responsible for their 'unwise' decisions.²⁵ Service providers' responses to risk can be driven by fear of blame, litigation, negative media attention, and reputational damage.²⁶

Public hearing 20 examined how disability services balance duty of care and dignity of risk. Counsel Assisting submitted that there was evidence that the service provider Life Without Barriers did not respect the right of resident 'Sophie' to dignity of risk and privacy and did not appropriately support her right to intimacy.²⁷

Some people with disability experience additional barriers

We have heard that some people with disability face additional barriers to exercising their autonomy, based on their type of disability, cultural and socio-economic background, gender or gender identity, sexuality, and age.²⁸ First Nations people with disability have described how guardianship and administration can result in disconnect from Country and culture.²⁹ During private sessions, we have heard about the difficulties experienced by people with disability from culturally and linguistically diverse backgrounds in navigating guardianship processes. One woman with disability from a culturally and linguistically diverse background described how the guardianship process was the backdrop to domestic violence.

Barriers to people with disability participating in decision-making

We have been told that people with cognitive disability are routinely disempowered, not believed and excluded from decision-making processes.³⁰ One disability support worker told us that, in her experience, disability service staff are pressured to 'go along with' the wishes of guardians in order to keep a client's funding, and that this may result in abuse and neglect.³¹

The need for greater understanding and access to supported decision-making

A recurring theme across the evidence and information provided to the Royal Commission has been supported decision-making as a way to realise the autonomy of people with disability.³² Support for decision-making has arisen across a number of public hearings held to date.

However, we have been told that in practice supported decision-making is generally not recognised as an alternative to substitute decision-making by tribunals, disability service providers, health professionals, other institutions and the broader community.³³

Movement towards supported decision-making

A number of Australian and international jurisdictions, sectors and organisations have started to move away from substitute decision-making toward supported decision-making.

Substitute decision-making refers to processes and regimes that involve decisions being made on another person's behalf. This approach removes legal capacity from a person, as a substitute decision-maker can be appointed against a person's will, and decisions are based on the 'best interests' of the person concerned, rather than their will and preferences.³⁴

Supported decision-making refers to processes and approaches that assist people to exercise their autonomy and legal capacity by supporting them to make decisions. This approach seeks to give effect to the will and preferences of the person requiring decision-making support.

Supported decision-making has also been flagged as an effective mechanism for addressing and safeguarding against elder abuse, a particular concern for people with dementia and older people with disability.³⁵

The shift from substitute to supported decision-making has been described as a significant human rights development, particularly for people with cognitive disability.³⁶ It aligns with article 12(3) of the *CRPD*:

States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

Supported decision-making better enables people with disability to exercise their autonomy. A range of stakeholders have highlighted the importance of introducing a nationally consistent approach that aligns with the *CRPD*.³⁷ The *CRPD* Committee has called on Australia to 'implement a nationally consistent supported decision-making framework' as recommended by the Australian Law Reform Commission (ALRC).³⁸ Nonetheless, implementation in law, policy and practice remains a challenge.³⁹

In Australia, evidence suggests that supported decision-making and substitute decision-making, including guardianship, are not mutually exclusive.⁴⁰ Rather, law reform bodies and researchers have examined the co-existence of guardianship and supported decision-making. Some research describes substitute decision-making as a legitimate part of a continuum when they are used as a last resort after all possible options to support a person with disability to make their own decisions have been exhausted.⁴¹

The sections below outline recent movements toward supported decision-making, both in Australia and overseas. The Royal Commission is considering the merits of these approaches as part of our inquiry.

Developments in Australia

In Australia, several government inquiries and initiatives have recommended increased supported decision-making for people with disability.

In 2014, the ALRC report, *Equality, Capacity and Disability in Commonwealth Laws* recommended that all jurisdictions reform relevant laws and legal frameworks to formally recognise and promote supported decision-making in line with four principles and a decision-making model.⁴²

The four Principles are:⁴³

- Principle 1: All adults have an equal right to make decisions that affect their lives and to have those decisions respected.
- Principle 2: 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: The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.
- Principle 4: Laws, legal frameworks and policies 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.

The ALRC's recommendations have been widely endorsed in Australia and recognised internationally.⁴⁴ Many submissions to the Royal Commission and responses to issues papers have also endorsed the recommendations.⁴⁵

Other major national inquiries have similarly recommended an increased focus on supported decision-making.⁴⁶

Victoria and Queensland have also recognised and incorporated support for decision-making in guardianship legislation, to varying extents.⁴⁷

Queensland requires a 'structured' approach to decision-making that starts by recognising the autonomy of the individual, before resorting to appointed substitute decision-making.

The steps include:

- recognition of the person's right to make their own decisions and, if possible, support for the person to make a decision
- recognition of the views, wishes and preferences expressed or demonstrated by the person

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- recognition of the person's views, wishes and preferences under the principle of substituted judgement
 - exercise of power under substitute decision-making.⁴⁸

In 2019, Victoria passed legislation to reform its guardianship system.⁴⁹ The Victorian reforms sought to implement the principles recommended by the ALRC.⁵⁰ Legislation now provides for the appointment and legal recognition of roles for supporters in decision-making.⁵¹ Subsequently, a 'supportive guardian' or 'supportive administrator' can be appointed to support a person to make and give effect to their own decisions about personal or financial matters.⁵² A supportive guardian or administrator cannot make decisions on a person's behalf.⁵³

Professor Ron McCallum AO and other legal commentators have considered the Victorian approach the closest an Australian jurisdiction has come to complying with human rights principles and the *CRPD*.⁵⁴ The introduction of the *Guardianship and Administration Act 2019* in Victoria saw a reduction in applications for guardianship orders.⁵⁵ A number of responses to issues papers have suggested that this Royal Commission consider the Victorian approach.⁵⁶

Recent reviews into guardianship and administration in New South Wales, Tasmania and the Australian Capital Territory have made recommendations on incorporating a formal supported decision-making scheme.⁵⁷ There have been no official government responses to these reviews.

Other statutory frameworks provide for supported decision-making in other ways. For example, the *National Disability Insurance Scheme Act 2013* recognises the role of informal supporters.⁵⁸ The *Aged Care Quality Standards* require organisations to provide support for decision-making.⁵⁹

In 2021, the federal Department of Social Services (DSS) released *Good Practice in Supported Decision-making for People with Disability* (DSS report).⁶⁰ The aim of this report was to develop guidelines for government stakeholders, statutory organisations and disability organisations on nationally consistent supported decision-making.

Developments internationally

There have also been a number of initiatives and approaches to implementing supported decision-making at the international level. Jurisdictions in Canada,⁶¹ the United States,⁶² Israel,⁶³ Argentina,⁶⁴ Peru,⁶⁵ and a number of European countries⁶⁶ have taken measures to formally recognise and implement supported decision-making.

Costa Rica, Colombia and Peru have eliminated all forms of guardianship for people with disability from their legal frameworks.⁶⁷ In Peru, this was achieved via legislative reform that repealed provisions that allowed for substituted decision-making regimes. These reforms introduced a supported decision-making system which recognised full legal capacity to people with disability who, except for certain cases, are able to freely appoint supports and safeguards through judicial or notary procedures.⁶⁸ The law does not immediately overturn current

guardianship arrangements, but instead transforms the system to designate supports and safeguards.⁶⁹ Research has highlighted the need for guidance on how these reform apply in practice, as some issues (such as conflict of interest) were not addressed in legislation and, in practice, some judges have responded to the reforms as a change in name only.⁷⁰

Other jurisdictions internationally retain guardianship as an option of last resort.⁷¹ Ireland, for example, introduced the *Assisted Decision Making (Capacity) Act* in 2015. While the Act incorporates supported decision-making approaches, section 38 allows for guardianship.⁷²

Canada is considered at the forefront of embedding alternatives to substitute decision-making in guardianship legislation.⁷³ A number of Canadian provinces have implemented supported decision-making models, building on earlier developments in Scandinavian countries.⁷⁴

In Alberta, legislation provides for supported decision-making and co-decision-making.⁷⁵ In British Columbia, a person can enter into a 'representation agreement', appointing representatives to help them make decisions or make decisions on their behalf. A representation agreement retains substitute decision-making as an option, but only if the person chooses that option. Regardless of whether the person chooses to appoint someone as a supporter or substitute decision-maker, the agreements emphasise respecting the person's wishes, beliefs and values.⁷⁶ However, research has found a limited uptake, largely due to a lack of trusting relationships with a person who could perform this role.⁷⁷

The United States has developed a model law on guardianship, which among other things requires a court to rule out supported decision-making as an option prior to appointing a guardian, conservator or other protective arrangement.⁷⁸ This model law has been enacted in two states, and further states are incorporating references to supported decision-making in their statutes.⁷⁹

Pilot programs

A number of trials and pilot programs in Australia and internationally have aimed to better understand how supported decision-making works in practice.⁸⁰ In Australia, pilot programs have taken place in South Australia, Victoria, New South Wales, Australian Capital Territory, Queensland and Western Australia.⁸¹ Most aimed to implement supported decision-making models for people with cognitive disability.

In 2021, the National Disability Insurance Agency (NDIA) published the outcomes of a consultation on supports for decision-making for NDIS participants.⁸² Building on these outcomes, the NDIA began co-designing a new Support for Decision Making policy and implementation plan in 2022.⁸³

The National Disability Advocacy Program (NDAP), funded by the DSS, is currently running a Decision Support Pilot, designed to assist people with 'limited decision-making capacity' navigate the NDIS.⁸⁴

While peer-reviewed studies are limited, these pilots provide a growing evidence base on the benefits of supported decision-making for people with disability.⁸⁵

Pilots in Massachusetts and New York aimed to provide supported decision-making as an alternative to guardianship.⁸⁶ Israel has also run a pilot involving people under guardianship with the aim to develop and formulate a supported decision-making model to disseminate to community members, professionals and policy makers.⁸⁷

For a small number of supported decision-makers, there was also the removal, or initiation of removal, of a guardianship or administration order during the pilot.⁸⁸

However, research commissioned by the Royal Commission suggests a need for further pilots to examine supported decision-making as an alternative to guardianship or financial administration orders, given the limited numbers of participants to date.⁸⁹

Proposals – potential reform directions

The following reform proposals are put forward for discussion at the roundtables. The proposals do not necessarily represent the considered views of all Commissioners.

Part 1: Supported decision-making

This section looks at possible reform directions to recognise and enable supported decision-making. It will be the focus of the first roundtable on **31 May 2022**.

National supported decision-making framework

The Royal Commission is considering a national supported decision-making framework, based on the ALRC's recommendations. The framework would include:

- principles to guide reform of federal, state and territory laws, policies and legal frameworks, as well as policies and practices of public and private bodies
- guidelines to support implementation
- a supported decision-making model.

A national approach to supported decision-making would have the advantage of increasing consistency across jurisdictions. It would also enable the implementation of a national safeguarding framework that prioritises the will, preferences and rights of a person with disability. National consistency in safeguarding would decrease the risk of violence, abuse, neglect or exploitation.

The national supported decision-making framework would encourage greater use of supported decision-making by tribunals, courts, health professionals, other institutions, and the broader community.⁹⁰ It should apply to:

- guardianship and administration (explored in Part 2)
- the NDIS
- health care
- supported accommodation
- the criminal justice system.

The national supported decision-making framework would also build the confidence and capacity of disability service providers to include best practice supported decision-making in their operations.⁹¹

Legislating elements of a supported decision-making framework would strengthen implementation.⁹² Legal recognition can change ‘social perceptions and actions’.⁹³

The considered national supported decision-making framework, comprising of principles, guidelines and a supported decision-making model, should:

- guide reform of Commonwealth, state and territory laws and policies, as well as public and private organisational practice
- promote co-designed pilots and trials of supported decision-making across service systems, including long-term funding for these
- accommodate the development of culturally safe models of supported decision-making, including for First Nations people, people from culturally and linguistically diverse backgrounds and other population groups
- increase awareness of supported decision-making as an alternative to substitute decision-making
- ensure substitute decision-making occurs only as a last resort, subject to safeguards.

Principles

The Royal Commission has considered the Principles recommended in the ALRC report. Based on the evidence and information gathered through this inquiry, the Royal Commission is considering an expanded list of eight principles.

Principle 1: Recognition of 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: Presumption of decision-making ability

All adults must be presumed to have ability to make decisions that affect their lives.

Principle 3: Respect for dignity and the right to dignity of risk

All adults must be treated with dignity and respect and supported to take risks to enable them to live their lives the way they choose, including in their social and intimate relationships.

Principle 4: Recognition of the role of informal supporters and advocates

The role of informal supporters and advocates who provide supported decision-making should be acknowledged and respected.

Principle 5: Access to support necessary to communicate and participate in decisions

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 6: Decisions directed by a person's own 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 7: Inclusion of appropriate and effective safeguards against violence, abuse, neglect or exploitation

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

Principle 8: Co-design, co-production and peer-lead design processes

People with disability and their representative organisations should be involved in the reform and development of laws, policies and legal frameworks.

Reform proposal 1: National supported decision-making principles

Australian, state and territory governments should embed the national supported decision-making principles in federal, state and territory laws, policies and legal frameworks. These principles form part of the legislative model of supported decision-making outlined in Reform proposal 8 below.

Public and private organisations should also use these principles to inform their policies and practice.

Discussion questions

1. Do you agree or disagree with the proposed national supported decision-making principles?
2. Are there any unintended consequences or barriers to implementation we need to consider?

Guidelines

The ALRC report recommended guidelines to assist with the implementation of their proposed principles. The guidelines focused on support; will, preferences and rights; and safeguards.⁹⁴ The Royal Commission's suggested guidelines draw on those recommended by the ALRC.

In addition, the Royal Commission suggests that further guidelines be considered to support the relevant principles on:

- decision-making ability
- respect for the right to dignity of risk
- recognition of informal supporters and advocates
- co-design, co-production and peer-led processes.

The following sub-sections outline the rationale for these guidelines.

Support

Support should enhance the ability of people with disability to make decisions and exercise control over their own lives. This includes the choice to have a supporter, choose the supporter, or to decline support.⁹⁵

The Royal Commission has considered the ALRC support guideline,⁹⁶ but suggests that the core elements of the process for supported decision-making should be included. This should incorporate aspects drawn from the DSS report on *Good Practice in Supported Decision-making for People with Disability*.⁹⁷

Reform proposal 2: Support guideline

People who require supported decision-making should be supported to make decisions and to participate in and contribute to all aspects of life.

The provision of support should ensure that:

- people who require supported decision-making should be able to choose to be assisted by a supporter, and to cease being supported at any time
- where a supporter is chosen, ultimate decision-making authority remains with the person who requires decision-making support
- supported decisions should be recognised as the decisions of the person who required supported decision-making.

Steps that should be undertaken in providing supported decision-making include:

- a question or issue is presented to a person with additional contextual information as required and alternatives
- the person requiring decision-making support consults with their preferred supporter/s
- the supporter must at all times seek to give effect to the 'will, preferences, and rights' of the person requiring decision-making support
- the person requiring decision-making support decides
- the decision is documented, acted upon, and is legally enforceable.

Discussion questions

1. Do you agree with the inclusion of the guideline on support?
2. Are there any unintended consequences or barriers to implementation we need to consider?

Will, preferences and rights

The ALRC's will, preferences and rights guidelines differentiate between supported and representative decision-making. The starting point, in both cases, is that decisions must be directed by the will and preferences of the person needing decision-making support.⁹⁸

The ALRC guidelines also require that, in cases where the will and preferences of a person cannot be determined, the focus should be on what the person's will and preferences would likely be. In the absence of a means to determine this, a new default standard is advocated, expressed not in terms of 'best interests' but of human rights.⁹⁹

The standard for how a representative should act in these circumstances requires a consideration of past information about decision-making choices. The ALRC report specified that a key source of such information is likely to be the person's family members, carers and other significant people in their life.¹⁰⁰

The Royal Commission considers there is merit in the ALRC's recommended will, preferences and rights guidelines.

Reform proposal 3: Will, preferences and rights guidelines

Supported decision-making

In assisting a person who requires supported decision-making, a person chosen by them as supporter must:

- support the person to express their will and preferences
- assist the person to develop their own decision-making ability.

In communicating will and preferences, a person is entitled to:

- communicate by any means that enable them to be understood
- have their cultural and linguistic circumstances recognised and respected.

Representative decision-making

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

- the person's will and preferences must be given effect
- 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
- 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
- a representative may override the person's will and preferences only where necessary to prevent harm.

Discussion questions

1. Do you agree with the inclusion of the guideline on will, preferences and rights?
2. Are there any unintended consequences or barriers to implementation we need to consider?

Safeguards

Safeguards prevent a person who requires decision-making support from risk of violence, abuse, neglect or exploitation. Other safeguards may be required to ensure supported decision-making arrangements genuinely respond to and reflect the wishes of a person with disability.¹⁰¹

Our present view is that the ALRC safeguards guidelines capture the essential elements that should be incorporated in relevant laws and legal frameworks.¹⁰² The safeguards guidelines also reflect the requirements in article 12(4) of the *CRPD* that all measures relating to the exercise of legal capacity provide for appropriate and effective safeguards.¹⁰³

Reform proposal 4: Safeguards guidelines

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

- the least restrictive of the person's human rights
- subject to appeal
- subject to regular, independent and impartial monitoring and review.

Supported decision-making

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

Discussion questions

1. Do you agree with the inclusion of the guidelines on safeguards?
2. Are there any unintended consequences or barriers to implementation we need to consider?

Decision-making ability

We have been told that, if a person with a disability is perceived to have diminished decision-making capacity, there is often an assumption that they do not understand their rights.¹⁰⁴ Contemporary approaches consider capacity as a spectrum, rather than something people do or do not possess. All people may require support to understand their rights at certain points in their lives, regardless of disability.¹⁰⁵

The ALRC report found that all adults, except in very limited circumstances, have some level of decision-making ability and should be entitled to make decisions expressing their will and preferences, even if they require varying levels of support to do so.¹⁰⁶ As part of its recommended support guidelines, a person's decision-making ability was central to assessing the requirement of supports in decision-making.¹⁰⁷

Recent law reform reports have also proposed including a presumption of decision-making ability as well as a statutory test of decision-making ability.¹⁰⁸ The New South Wales Law Reform Commission considered that its recommended decision-making ability provisions should be applied by anyone who bears the onus of deciding whether a person lacks the relevant decision-making ability for a particular decision. This includes the tribunal, any representative, supporter, person responsible, or any witness to an agreement. It did not place an obligation on medical professionals who report on matters relevant to the determination of a person's decision-making ability.¹⁰⁹

We are attracted to the proposed decision-making ability guideline recommended by the New South Wales Law Reform Commission.¹¹⁰

Reform proposal 5: Decision-making ability guideline

A person has decision-making ability if they are able to make a decision with practical and appropriate support, and at the time when the decision needs to be made:

- understand the relevant information
- understand the nature of the decision and the consequences of making or failing to make that decision
- retain the information to the extent necessary to make the decision
- use the information or weigh it as part of the decision-making process
- communicate the decision in some way.

A person must not be determined to not have decision-making ability unless all practical steps have been taken to provide the person with appropriate support to make and communicate a decision.

In assessing what support is required in decision-making, the following must be considered:

- all adults must be presumed to have ability to make decisions that affect their lives
- a person must not be assumed to lack decision-making ability on the basis of having a disability
- a person's decision-making ability must be considered in the context of available supports
- a person's decision-making ability is to be assessed, not the outcome of the decision they want to make
- a person's decision-making ability will depend on the kind of decisions to be made
- a person's decision-making ability may evolve or fluctuate over time.

Discussion questions

1. Do you agree with the inclusion of the guideline on decision-making ability?
 - a. What skills and experience are likely to be required for a person to carry out a decision-making ability test?
 - b. Should public officials be permitted to undertake this test with appropriate guidance?

Recognition of informal supporters and advocates

We have been told there is a need for legislative recognition of the role of informal supporters and advocates in providing supported decision-making.¹¹¹ ‘Informal supporters’ can include family members, and paid and unpaid supporters.

We have been told there is a widespread lack of understanding of the role of informal supporters, and that informal supporters should be able to access information to convey it to the person they are supporting.¹¹²

There would be benefits in formalising supported decision-making arrangements so that they are better understood by supporters, representatives and third parties.¹¹³ Some third parties, such as financial institutions or people who wish to enter into contracts, may otherwise refuse to recognise a supporter, for example, attempting to access information. This may be due to fears of breaching privacy requirements or fears of a supporter exerting undue influence or coercion.¹¹⁴

Concerns have been expressed that informal supported decision-making should not be displaced by new legal arrangements. A risk identified in legislating supported decision-making is that it undermines effective informal supported decision-making arrangements.¹¹⁵

Our present view is that the role of informal supporters should be formally recognised. While the ALRC support guideline acknowledged the role of family members, carers or others,¹¹⁶ a dedicated guideline would promote recognition of informal supporters in practice.

Reform proposal 6: Recognition of informal supporters guideline

The role of persons who provide informal supported decision-making should be acknowledged and respected. Informal supporters include family members, carers, advocates or other significant people chosen to provide support.

Informal support arrangements should not be displaced. The national decision-making principles in Reform proposal 1 should also apply to informal supporters.

Discussion questions

1. Do you agree with the inclusion of a guideline to recognise the role of informal supporters?
 - a. What is needed to ensure information protection and prevent potential privacy breaches?
2. Are there any unintended consequences or barriers to implementation we need to consider?

Respect for the right to dignity of risk

'Dignity of risk' has arisen in the Royal Commission's Public hearings, submissions and private sessions. We have been told that the lives of people with disability are often restricted as a result of concern that they may not have a good understanding of risk and that service providers will be held responsible for their decisions.¹¹⁷

During Public hearing 20: *Preventing and responding to violence, abuse, neglect and exploitation in disability services (two case studies)*, we heard about the difficulties service providers have in balancing their duty of care and supporting a person's right to dignity of risk.¹¹⁸

We have been told that risk is fundamental to the human experience.¹¹⁹ In Public hearing 6: *Psychotropic medication, behaviour support and behaviours of concern*, we heard that that everyone in the community behaves in a way that involves risk and that 'having choice in our lives involves risk'.¹²⁰ Everyone is entitled to experience the dignity of risk – with support if necessary – and to make and learn from mistakes.¹²¹

Decision-making support has been proposed as a way to balance dignity of risk and duty of care.¹²² The ALRC report noted that supported decision-making processes recognise dignity of risk and that people should be empowered with information to make decisions, including 'bad ones'.¹²³

The Aged Care Quality Standards explicitly refer to 'consumer dignity and choice' and require that organisations demonstrate that '[e]ach consumer is supported to take risks to enable them to live the best life they can'.¹²⁴ The Standards also require organisations to provide support for decision-making, including to make decisions about their own care, and how it is delivered, and make connections with others and maintain relationships of choice, including intimate relationships.¹²⁵

For these reasons, the Royal Commission considers there is value in proposing an additional principle and guideline on the right to dignity of risk.

Reform proposal 7: The right to dignity of risk guideline

People should be supported to take risks to enable them to live their lives the way they choose, including for everyday decisions and interpersonal relationships. This includes actions to recognise a person's strengths and empower them to be independent:

- the supporter, representative, or organisation need to take a balanced approach to managing risk and respecting a person's rights
- if a person makes a choice that is possibly harmful to them, then the supporter, representative, or organisation should help the person understand the risk and how it could be managed
- where organisations have other responsibilities for the health and safety of the workforce, the organisation should show how they involve the person to look for solutions that have the least restriction on the person's choices and autonomy.

Discussion questions

1. Do you agree with the inclusion of a guideline on the right to dignity of risk?
2. Are there any unintended consequences or barriers to implementation we need to consider?

The Royal Commission is interested in the practical effect of all the guidelines discussed above.

Discussion questions

1. What, if any, legal or regulatory effect should the guidelines have?
2. Should there be legal duties for public agencies and bodies to secure supported decision-making for people who need it?

Supported decision-making model

This section looks at the introduction of a national model for supported decision-making.

The ALRC report recommended the introduction of a ‘Commonwealth decision-making model’ as a statutory mechanism in relevant laws and legal frameworks.¹²⁶ It recommended a legislative model, based on the roles of ‘supporters’ and ‘representatives’, that should be embedded into relevant Commonwealth laws related to the NDIS, social security, the justice system, and restrictive practices. This included recommending key elements of the model, namely:

- amending the objects or principles provisions of relevant legislation
- the appointment, recognition, functions and duties of supporters and representatives
- appropriate and effective safeguards.¹²⁷

To ensure the effective operation of this model and its interaction with state and territory systems, the ALRC recommended mechanisms to share information between Australian, state and territory government departments and agencies on appointments of supporters and representatives.¹²⁸

The ALRC further recommended state and territory governments review laws and legal frameworks to ensure they are consistent with its recommended principles and the Commonwealth decision-making model.¹²⁹ Although the ALRC focused on Commonwealth laws, it highlighted the need for ‘parallel reform of state and territory guardianship and administration

laws' to integrate with the recommended Commonwealth model.¹³⁰ It noted practical difficulties and potential conflicts between Commonwealth, state and territory systems if state and territory systems retain existing decision-making systems.¹³¹ The ALRC suggested legislative reform may also be required to align duties and responsibilities between Commonwealth, state and territory legislation.¹³²

The ALRC model encourages the adoption of supported decision-making at a national level and introduces mechanisms for the appointment of 'supporters' (for people who may require decision-making support) and 'representatives' (for circumstances in which a person may desire, or require, someone else to make decisions for them).¹³³ The terms 'supporter' and 'representative' have also been adopted in other law reform reports examining guardianship.¹³⁴

The ALRC model recognises several 'tiers' of supporters, reflecting that, in practice, supported decision-making occurs on a spectrum. It also retains substitute decision-making as a last resort.¹³⁵ However, we note that, even where decision-making is legally attributed to a substitute or representative, the person's will and preferences may remain central and be reflected in the decision. This approach, referred to as 'substituted judgment', is recognised as being part of the spectrum of supported decision-making. Research suggests substituted judgment is better aligned with the intent of 'will and preferences' than a 'best interests' approach.¹³⁶

Victoria and Queensland have implemented supported decision-making models which comprise of some elements of the ALRC's model. For example, Queensland has updated its guardianship legislation to include general principles and health care principles that have greater consistency with human rights, particularly the *CRPD*.¹³⁷ These principles include the presumption of capacity, participation in decision-making, maintaining supportive relationships and maintaining culture, language, values and beliefs.¹³⁸ These general principles must be applied when making decisions on behalf of an adult with impaired decision-making capacity.

In Victoria, legislation was reformed to introduce supportive guardianship and supportive administration orders, allowing appointees to support a person with disability to make decisions on personal or financial matters respectively.¹³⁹ Other reforms included:

- expansion of the presumption of decision-making capacity to include presumption to make decisions with 'practicable and appropriate support' unless evidence to contrary¹⁴⁰
- a new standard of decision-making which shifts away from the best interest standard, focusing on involvement of the person with disability and their will and preferences.¹⁴¹

Supported decision-making models in the context of guardianship are discussed further in Part 2 of this paper.

The Royal Commission considers that the Australian Government and state and territory governments should adopt the terms ‘supporter’ and ‘representative’ to provide greater clarity and understanding in approaches to decision-making.¹⁴² Public and private organisations should also adopt this terminology.

The Royal Commission sees merit in a supported decision-making model based on the ALRC ‘Commonwealth decision-making model’.

Reform proposal 8: Supported decision-making model

The Australian Government, state and territory governments should introduce into relevant laws and legal frameworks the proposed supported decision-making model:

- the objects and principles provisions in legislation concerning decision-making by people who require supported decision-making should reflect the national supported decision-making principles in Reform proposal 1
- the concept, duties and responsibilities of a supporter should be consistent with Reform proposal 9
- the concept, duties and responsibilities of a representative should be consistent with Reform proposal 10
- the appointment and conduct of supporters and representatives should be subject to appropriate and effective safeguards.

The Australian government should embed this model in relevant Commonwealth legislation to provide for legal recognition of supporters and representatives, including provisions for their appointment, removal and associated safeguards. This should include (but not be limited to) the *National Disability Insurance Scheme Act 2013* (Cth); the NDIS Rules; the *Social Security (Administration) Act 1999* (Cth); and the *Aged Care Act 1997* (Cth).

The state and territory governments should embed this model in relevant state and territory laws, including guardianship and administration legal frameworks.

Discussion questions

1. Do you agree with the introduction of this supported decision-making model nationally? Is the model applicable to all relevant laws and legal frameworks across jurisdictions at both the Commonwealth and state and territory level?
2. Are there any unintended consequences or barriers to implementation we need to consider?

Reform proposal 9: Supporters

A supporter assists a person who requires supported decision-making and may:

- obtain and disclose personal and other information on behalf of the person, and assist the person to understand information
- provide advice to the person about the decisions they might make
- assist the person to communicate the decisions
- endeavour to ensure the decisions of the person are given effect.

Relevant Commonwealth, state and territory laws and legal frameworks should provide that supporters of persons who require supported decision-making must:

- support the person to make decisions
- support the person to express their will and preferences in making decisions
- act in a manner promoting the personal, social, financial, and cultural wellbeing of the person
- act honestly, diligently and in good faith
- support the person to consult, as they wish, with existing appointees, family members, carers and other significant people in their life in making decisions
- assist the person to develop their own decision-making ability.

An 'existing appointee' should be defined to include existing supporters and representatives and a person or organisation who, under federal, state or territory law, has guardianship of the person, or is a person formally appointed to make decisions for the person.

Discussion questions

1. Do you agree with the proposal to introduce and standardise the role of supporters nationally?
2. Are there any unintended consequences or barriers to implementation we need to consider?

Reform proposal 10: Representatives

A representative assists a person who requires supported decision-making or, where necessary, makes decisions on their behalf and may:

- obtain and disclose personal and other information on behalf of the person, and assist the person to understand information
- provide advice to the person about the decisions that might be made
- communicate the decisions
- endeavour to ensure the decisions made are given effect.

Relevant federal, state and territory laws and legal frameworks should provide that representatives of persons who require supported decision-making must:

- support the person to make decisions or make decisions on their behalf reflecting their will and preferences
- where it is not possible to determine the will and preferences of the person, determine what the person would likely want based on all the information available
- where it is not possible to determine the best interpretation of the person's will and preference, consider the person's human rights relevant to the situation
- act in a manner promoting the personal, social, financial and cultural wellbeing of the person
- act honestly, diligently and in good faith
- consult with existing appointees, family members, carers and other significant people in their life in making decisions
- assist the person to develop their own decision-making ability.

An 'existing appointee' should be defined to include existing supporters and representatives and a person or organisation who, under federal, state or territory law, has guardianship of the person, or is a person formally appointed to make decisions for the person.

Discussion questions

1. Do you agree with the proposal to introduce and standardise the role of representatives nationally?
2. Are there any unintended consequences or barriers to implementation we need to consider?

Safeguard mechanisms

Safeguards are needed to minimise the risk of undue influence and coercion, recognising the unequal relationships between people being supported and supporters and representatives.¹⁴³

Legal scholars have raised concerns that formalising support relationships in legal frameworks may 'place the "bar" too high, deterring less formal involvement'.¹⁴⁴ This may 'risk diluting the perceived legitimacy of informal supporters'.¹⁴⁵

It may also prove challenging for recognised supporters to determine when a person's decision-making ability has declined to the extent that supported decision-making, according to legislation, no longer works.¹⁴⁶

The ALRC report proposes safeguards, including:¹⁴⁷

- the recommended duties of supporters
- the ability of the person who requires decision-making support to revoke the appointment at any time
- provision for the appointment of more than one supporter
- guidance and training for people who require decision-making support, their supporters, and Commonwealth departments and agencies interacting with them.

In respect of representatives, the ALRC report considered that appropriate safeguards are dependent on the decision-making context.¹⁴⁸ It suggested that the Australian Government should consider the following in any Commonwealth representative scheme:¹⁴⁹

- mechanisms for review and appeal of the appointment of representatives, including on the application of any interested party
- the potential for representatives to be periodically required to make declarations regarding compliance with their duties
- reporting obligations on representatives with respect to decisions, for example by provision of a report, inventory or accounts
- the powers of any Commonwealth body conferred with jurisdiction to appoint a representative should include the power to respond to instances of abuse, neglect or exploitation
- the role of Commonwealth departments and agencies in monitoring, auditing and investigating the conduct of representatives
- the broader applicability of safeguards envisaged under a NDIS quality assurance and safeguards framework.

The Royal Commission is considering approaches to safeguard mechanisms that could be enshrined in legislation, including:

- restrictions on who can act as a legally recognised supporter to decrease the risk of exploitation or manipulation of decision-makers by supporters, an approach taken in Ireland and the United States¹⁵⁰
- legislating duties on supporters to, for example, refrain from undue influence¹⁵¹
- expressly making the supporter relationship one which comes with fiduciary duties¹⁵²
- education and supervision of supporters¹⁵³
- establishment of formal registers of support agreements¹⁵⁴
- appointed ‘monitors’ who have oversight of the relationship between the person with a disability and the person appointed¹⁵⁵
- periodic reporting requirements to a government body with oversight responsibilities of supporters, as is the case in Ireland¹⁵⁶
- nomination of a person’s own safeguards including reporting, audits, periodic supervision, interview and information requests, as can be done in Ireland¹⁵⁷
- dedicated agencies or government bodies to assist in oversight of supported decision-making¹⁵⁸
- court or tribunal review of support arrangements¹⁵⁹
- requirements to document the process for a decision arrived at by the person requiring decision-making support to ensure that it reflects the ‘will and preferences’ of the person requiring support.¹⁶⁰

Beyond duties imposed directly by legislation, legal frameworks may establish regulatory systems of standards which may more readily recognise aspects of supported decision-making within particular sectors. For example, the Aged Care Quality Standards framework provides in Standard 1 (Consumer dignity and choice) recognition that ‘consumers who need support to make decisions are expected to be provided with access to the support they need to make, communicate and take part in decisions that affect their lives’.¹⁶¹

Reform proposal 11: Safeguard mechanisms

The Australian Government and state and territory governments should ensure the implementation of safeguards for supporters and representatives. These should be consistent with the safeguards guideline outlined in Reform proposal 4.

Safeguard mechanisms may include:

- appointment of monitors
- registration of arrangements
- reporting requirements
- police checks for the appointment of supporters
- mechanisms and procedures for review, appeal and monitoring of support and representative arrangements
- recordkeeping and audit requirements on supporters and representatives
- reporting obligations on representatives for certain decisions, for example, by provision of a report, inventory or accounts.

Discussion questions

1. Do you agree that all the Australian, state and territory governments should implement safeguards for supporters and representatives, such as those listed above?
2. Do you consider any of the possible safeguards in the list above to be inappropriate or ineffectual?
 - a. Are any non-statutory safeguards needed?
 - b. Should supporters be required to best demonstrate that a decision made by a person requiring supported decision-making is in fact a decision of that person?
3. Are there any unintended consequences or barriers to implementation we need to consider?

Interpretative declaration in relation to article 12

The Australian Government has set out its understanding of article 12 of the *CRPD* through an interpretative declaration:

Australia recognizes that persons with disability enjoy legal capacity on an equal basis with others in all aspects of life. Australia declares its understanding that the Convention allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards.¹⁶²

The Australian Government reiterated this position at the Royal Commission's Public hearing 18: *The human rights of people with disability and making the Convention on the Rights of Persons with Disabilities a reality in Australian law, policies and practices*.¹⁶³

There are differing views on this interpretative declaration, particularly in relation to the role of substitute decision-making. Many disability advocates have recommended that it should be withdrawn.¹⁶⁴ We have been told it prevents reform of existing systems and allows for continued human rights violations, including the denial of legal capacity.¹⁶⁵

The ALRC report suggested the differing views about the effect of the interpretative declaration are driven by conceptual confusion, and that this impedes reform.¹⁶⁶ The ALRC report suggested that conceptual clarity could be achieved, regardless of whether the interpretative declaration is withdrawn.¹⁶⁷ It considered that, in addition to the rollout of the NDIS, the adoption of the National Decision-Making Principles would promote compliance with the *CRPD*.¹⁶⁸

Implementing a national supported decision-making framework

This section looks at the different ways in which a national supported decision-making framework could be put into practice.

Education, training and capacity building

Education and training on supported decision-making can contribute to the fundamental change that is required to change attitudes, alter practices and ultimately facilitate the inclusion of all people with disability in Australian society.¹⁶⁹ Formalising supported decision-making alongside substitute decision-making may create confusion about how the regimes interact.¹⁷⁰

Dedicated resources, training and education are required to embed supported decision-making in the everyday practices of the disability support sector and assist people with disability, their families and disability support workers to understand the core principles of supported decision-making.¹⁷¹

Research and supported decision-making models trialled in Australia have highlighted the need for greater understanding about effective programs for delivering support for decision-making.¹⁷² Recent research has focused on approaches for transitioning from substitute to supported decision-making through capacity-building programs for supporters of people with cognitive disabilities.¹⁷³

The La Trobe Decision-making Framework is one example of a promising practice tool to guide decision-making support for people with cognitive disability.¹⁷⁴ The framework outlines steps, principles and strategies to support decision-making. It focuses on understanding the will and preferences of people with cognitive disabilities and guides those who provide support, including families, support workers, guardians and health professionals, with practical strategies.¹⁷⁵

Obligations to provide supported decision-making could be reflected in policies, instructional materials and codes of practice in different service sectors. A number of respondents to the *Health care for people with cognitive disability issues paper* raised concerns about the lack of knowledge and skills of health professionals in understanding their obligations to provide supported decision-making.¹⁷⁶

It has been suggested that the NDIS Quality and Safeguards Commission should consider the circumstances in which training on supported decision-making should be mandatory, and that NDIS pricing arrangements should reflect the provision of such training.¹⁷⁷

Other Commonwealth, state and territory agencies could also provide training on supported decision-making and how it applies in a particular setting.¹⁷⁸ For example, the Australian Health Practitioner Regulation Agency could ensure that all health practitioners are trained and skilled in supported decision-making and capacity assessment, in line with legislative requirements.¹⁷⁹

Reform proposal 12: Education, training and capacity building

The Australian government, state and territory governments should ensure that accessible and culturally appropriate information, guidance and training on supported decision-making is provided to:

- people who require supported decision-making, on their right to support and how this applies in different contexts
- supporters and representatives, to enable them to understand their functions and duties
- employees and contractors of federal, state and territory agencies who engage with people who require supported decision-making, their supporters and representatives.

Responsibility for the development and delivery of this information, guidance and training on supported decision-making should sit with the proposed governance body in Reform proposal 13.

Discussion questions

1. Do you agree with the proposal on education, training and capacity building on supported decision-making?
2. Are there any unintended consequences or barriers to implementation we need to consider?

Governance

To implement the national supported decision-making framework, commitment is needed at the federal, state and territory levels to promote the right of people with disability to make their own decisions.

Supported decision-making pilots have suggested there would be value in a stand-alone body, such as an agency, service or co-ordinating group, to promote and develop supported decision-making. This body could work with people with disability, their families and service providers to coordinate supported decision-making.¹⁸⁰

The Royal Commission is considering the merits of establishing such a body to oversee and monitor the implementation of the national supported decision-making framework.

In Scotland, the Centre for Excellence in Supported Decision-Making has been tasked by the Scottish Mental Health Commission to provide expertise; work with the Scottish Government to develop policy and practice changes; roll out training; and build capacity for supported decision-making.¹⁸¹

Funding responsibilities

Legal and policy reforms may require funding and long-term support for implementation if their intended benefits are to be realised for people with disability.¹⁸²

We have been told that the Australian Government and state and territory governments should determine an appropriate supported decision-making framework and funding model for non-NDIS participants.

Funding for NDIS participants may occur through their NDIS plan.¹⁸³ The NDIA has suggested the following approaches to funding:

- adding professional supported decision-making services as a line item that could be funded in individual participant plans
- continue funding volunteer support for decision-making programs and consider the feasibility of rolling out volunteer programs nationally.¹⁸⁴

There could also be a continuous funding stream to ensure the development of best practice guidance models and resources across different service system contexts.

Transitional implementation

A commitment to cultural change is also needed to help the broader community understand that people with disability have the right to make decisions about their lives.

The Royal Commission is considering whether a phased approach is needed to implement a supported decision-making regime. We have been told urgent action is needed to promote greater awareness and use of supported decision-making in practice.¹⁸⁵ However, past reports have highlighted that transitional changes are necessary to fully implement supported decision making, such as building community capacity, development and outreach activities.¹⁸⁶

A dynamic or 'living' framework that allows for progress over time would accommodate the need for immediate action to promote greater awareness and use of supported decision-making, while also building the evidence base for best practice supported decision-making models across different service setting contexts.

Reform proposal 13: Establishing a governance body

The Australian government, together with state and territory governments, should establish an independent body to oversee and monitor the implementation of the national supported decision-making framework. This body should:

- be led by people with disability and their representative organisations
- promote the development of supported decision-making models across different settings and contexts, including for different cohorts and groups of people
- provide leadership and facilitate the sharing of best practices and research
- provide training on supported decision-making
- support government agencies and organisations in developing supported decision-making resources, tools and materials
- build community capacity in supported decision-making.

This body should consult and work with the Australian Guardianship and Administration Council to ensure coordination across relevant state and territory-based service systems.

Discussion questions

1. Do you agree with the proposal to establish a governance body, in line with the parameters above?
 - a. Should the governance body have further functions and responsibilities?
 - b. Could an existing governance body implement and monitor the national supported decision-making framework?
2. Are there any unintended consequences or barriers to implementation we need to consider?
 - a. Is a phased approach needed to implement a national supported decision-making framework? If so, how should the steps be staged?
 - b. How should the impact of a national supported decision-making framework be measured over time? Should there be ongoing evaluations and periodic reports?

Part 2: Guardianship

This section looks at proposals to reform guardianship and administration arrangements. It will be the focus of the second roundtable on **1 June 2022**. It builds on Part 1 of this paper. It will also build on the discussion at the first roundtable to focus on how to apply the proposed supported decision-making model (Reform proposal 8) within Australia's guardianship and administration legal framework.

Australia may face challenges agreeing a national best practice approach as guardianship and mental health legal frameworks are within the jurisdiction of states and territories.¹⁸⁷ The benefits of national consistency should be weighed against the potential disadvantages of a uniform scheme that fails to appropriately respond to the socio-legal particularities of each jurisdiction.¹⁸⁸

A national 'best practice' model of guardianship

A role for supported decision-making

Recent state and territory reviews into guardianship in Australia have recommended the introduction of supported decision-making models to operate alongside substitute decision-making.¹⁸⁹

Consistent with these reviews, the Royal Commission is proposing greater incorporation of supported decision-making within the guardianship and administrative system. This reform of the guardianship system would sit alongside greater reliance on supported decision-making across Australia in place of guardianship (see Part 1 above).

The discussion below also considers ways that states and territories can reduce the number of people subject to guardianship and administration orders, and the length of time for which they are subject (see Transition points). The reforms considered in this paper would have the effect of transitioning Australia to a system based on 'supporters' and 'representatives', with a strong emphasis on supported decision-making, and representative arrangements used truly as a last resort in line with safeguards.

A focus on decision-making ability

Australian states and territories take different approaches to assessment of a person's capacity in the course of guardianship and administration matters. In some jurisdictions, a person must have a disability for a substitute decision-making order to be made, while in others, disability is not a precondition.¹⁹⁰

Recent guardianship reviews in New South Wales and Tasmania proposed the removal of disability as a precondition for substitute decision-making, on the basis that the focus should be on a person's decision-making ability, rather than their disability.¹⁹¹ It was considered that this would also ensure people with disability have the equal right to make a decision that might be considered by others to be 'irrational' or 'poor'.¹⁹²

The reviews in New South Wales and Tasmania proposed a presumption of decision-making ability as well as a statutory test of decision-making ability to replace the traditional approach based on ‘capacity’ tests.¹⁹³

Within the national supported decision-making principles and guidelines, explored in Part 1, the Royal Commission is proposing greater recognition for decision-making ability. This includes a proposed principle and an associated guideline on the presumption of decision-making ability, including determining decision-making ability, outlined in Reform proposals 1 and 5.

Approaches to incorporating supported decision-making in guardianship regimes

Supported decision-making may be implemented alongside guardianship and administration arrangements in a number of ways. Some different approaches taken in Australian and international jurisdictions are outlined below.

Requirement to first resort to supported decision-making in guardianship regimes

Some states and territories require supported decision-making be attempted before recourse to substitute decision-making within guardianship and administration legislation.¹⁹⁴ Relevant guardianship legislation in Queensland includes a structured decision-making framework which prioritises supported decision-making and the least restrictive approach before resorting to substitute decision-making.¹⁹⁵

A similar approach has been taken in English and Welsh legislation, with guiding principles requiring that a ‘person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success’.¹⁹⁶ However, evaluation of this legislation by the House of Lords Select Committee on the Mental Health Act 2005 found the Act was poorly implemented.¹⁹⁷ It concluded that there was a lack of understanding of the Act’s principles, in particular by health and social care professionals, and a ‘fundamental change of attitudes among professionals is needed in order to move from protection and paternalism to enablement and empowerment’.¹⁹⁸

Legal recognition of supporters within guardianship regimes

Another mechanism to embed supported decision-making into existing frameworks has been to legally recognise people in supporter roles. This has occurred in Victoria,¹⁹⁹ Alberta,²⁰⁰ Quebec,²⁰¹ Texas,²⁰² Ireland,²⁰³ and a number of European countries.²⁰⁴

A legally recognised supporter differs from a legally recognised substitute because there is no transfer of legal powers of decision-making away from the person.²⁰⁵ Instead, the appointments provide supporters with authority to access information on the supported person’s behalf, or help the person communicate their decision. The appointments also provide clarity for third parties interacting with the supported person and their supporter.²⁰⁶

In jurisdictions where supporters can be legally recognised, they may also be judicially appointed as an alternative to a guardian or administrator. This is the case in Victoria and Peru.²⁰⁷ Under this approach, a court or tribunal chooses a person's supporter, rather than the person themselves.²⁰⁸ However, research suggests this is less restrictive than appointment of a substitute decision-maker and appears more consistent with the goals of supported decision-making.²⁰⁹

There has been little evaluation of how supported decision-making works when a person is also subject to a formal substitute decision-making arrangement. Evidence from Israel suggests the appointment of a supporter concurrently with a guardian is ineffectual, as the supporter cannot perform their role in assisting the person when subject to the guardian's approval.²¹⁰

Appointment of co-decision makers

'Co-decision-making' is a less common legal arrangement, under which a person is able to appoint a co-decision-maker and decisions are jointly made by a person and their co-decision maker.

Co-decision-making has been legally recognised in Canada and Ireland.²¹¹ Data on the uptake of co-decision making in Canada is limited.²¹² In the Irish context it has been suggested that it will be useful in cases of early-stage dementia.²¹³

Empirical evidence on how co-decision-making operates as a form of supported decision-making is limited.²¹⁴ It has been critiqued as not complying with article 12 of the *CRPD*.²¹⁵ Other concerns include how co-decision making interacts with existing laws on consent to medical treatment, if and how liability would be apportioned, and how to safeguard against undue influence by a co-decision-maker.²¹⁶

Co-decision-making approaches have not gained traction in Australia. The New South Wales Law Reform Commission and Tasmanian Law Reform Institute decided against introducing a legislated co-decision-making scheme due to limited support.²¹⁷ However, the Victorian Law Reform Commission and the ACT Law Reform Advisory Council have recommended the approach.²¹⁸

Self-appointed representatives

In Australia, people can execute legally binding instruments that appoint another person to act on their behalf in the future, at a time when they will be unable or unwilling to make decisions themselves. These appointments may be in the form of enduring powers of attorney, enduring guardianship arrangements or advance directives.

If the instruments provide for the appointee to make decisions according to the person's 'will and preferences' and not their 'best interests' then they may be consistent with the *CRPD* Committee's understanding of supported decision-making.²¹⁹ However, concern has been expressed in research about the 'low and differential take-up' of these mechanisms due to factors such as race, ethnicity, education and other variables.²²⁰

Reform proposal 14: National ‘best practice’ model of guardianship

State and territory governments should reform guardianship and administration legislative frameworks to be consistent with the proposed national ‘best practice’ model of guardianship, implementing the supported decision-making principles outlined in Reform proposal 1 and the supported decision-making model in Reform proposal 8.

All Australian jurisdictions should adopt the model to provide greater consistency in approaches to guardianship and administration.

The Australian Guardianship and Administration Council should coordinate implementation of a national ‘best practice’ model of guardianship that:

- is based on a presumption of decision-making ability
- incorporates features and methods of supported decision-making
- maintains the role of informal supported decision-making.

Discussion questions

1. Do you agree with the implementation of a national ‘best practice’ model of guardianship? Is the Australian Guardianship and Administration Council the right body to coordinate this?
2. If not, what changes do you suggest and why?
3. Are there any unintended consequences or barriers to implementation we need to consider?

Best practice safeguards in guardianship

Safeguards within guardianship and administration legislation aim to prevent abuse, neglect or exploitation, and adequately respond when it occurs.²²¹

Currently, state and territory guardianship and administration systems provide a number of safeguards to prevent abuse, conflicts of interest and undue influence. These include:

- limits on when a tribunal can make a guardianship or financial management order
- eligibility criteria for potential guardians and administrators
- principles that guardians and financial managers must follow
- periodic reviews and oversight by tribunals.

However, we have heard that, despite the safeguards currently included in guardianship and administration legal frameworks, experiences of abuse, neglect and exploitation continue to occur.

The Australian Guardianship and Administration Council has developed the National Standards of Public Guardianship and National Standards for Financial Management.²²² These include standards on:

- providing information
- supporting decision-making capacity
- ascertaining will and preferences
- advocacy and protection
- decision-making
- recording information
- financial decision-making and investment
- participating in guardianship reviews
- professional development
- privacy and confidentiality requirements.²²³

These standards provide minimum expectations of staff in Offices of the Public Guardian when acting as legal decision-makers on behalf of others, and benchmark standards of service by administrators and financial managers when managing a person's financial affairs.²²⁴ The National Standards are a voluntary code and do not have force of law. It is not clear how and whether states and territories are meeting these standards.

Alternative dispute resolution

Alternative dispute resolution is broadly supported as a method to resolve conflict in a less formal way than through court or tribunal proceedings.

Several recent guardianship reviews have included recommendations to include mediation powers in relevant guardianship and administration legislation. Tasmania and New South Wales have recommended expanding the role and powers of the Public Advocate to facilitate mediation between parties.²²⁵

Mediation is available in some jurisdictions in limited circumstances. For example, in South Australia, the Public Advocate can mediate disputes relating to advance care directives and consent to medical treatment.²²⁶ In Queensland, the Public Guardian has power to mediate and conciliate between adults with 'impaired capacity', substitute decision-makers and other parties such as health providers.²²⁷

Monitoring and review mechanisms

Monitors who supervise supported decision-making arrangements can reduce the potential for inadvertent exercises of undue influence or conflicts of interest.²²⁸ In British Columbia, a monitor may visit and speak with a supported person, obtain accounts and records from their supporter, and inform the Public Trustee or Guardian if there is reason to believe the supporter is not complying with their duties.²²⁹

Further options for safeguarding include formal registers of support agreements, or dedicated government agencies to assist in oversight of supported decision-making.²³⁰ However, a number of law reform bodies have suggested that a registration scheme would have to be mandatory and inexpensive in order to be effective.²³¹

Recently, the New South Wales Law Reform Commission excluded both monitors and registration requirements as safeguarding components of its supported decision-making framework due to lack of support from stakeholders.²³²

Complaint and investigation processes

Some states and territories provide Public Guardians and Public Advocates with powers to investigate complaints or allegations that a person is under inappropriate guardianship, being exploited or abused, or in need of guardianship.²³³ In some cases, multiple agencies have investigation powers.

The New South Wales Law Reform Commission suggested that the recommended Public Advocate should provide a central point of contact to receive complaints or allegations and refer them to the most appropriate agency. In cases where there is no other avenue to pursue investigations, the Public Advocate would lead the investigation.²³⁴

Accountability mechanisms

Law reform bodies have recommended different approaches on the introduction of criminal or civil penalties for breaches of duty under guardianship and administration legislation.

Victoria has introduced new compensation and offence provisions that allow the Victorian Civil and Administrative Tribunal, or the Supreme Court to order a guardian or administrator to:

- compensate a person for a loss caused by the guardian or administrator contravening the *Guardianship and Administration Act 2019* (Vic)
- penalise a guardian or administrator who dishonestly uses their appointment to gain financial advantage or to cause a loss to the represented person.²³⁵

These offence provisions apply to guardians,²³⁶ administrators,²³⁷ supportive guardians,²³⁸ and supportive administrators.²³⁹

The Northern Territory also has offences for decision-makers who intentionally engage in conduct that fails to comply with the duties of decision-makers, or is not in accordance with the guiding principles of the legislation, and who are reckless in relation to the adult.²⁴⁰ A higher penalty is imposed where the decision-maker does so with the intention of obtaining a benefit for themselves or another person.²⁴¹

Independent legal representation

Legal and advocacy bodies have identified a need for mandatory legal representation for people subject to guardianship and administration applications.²⁴² Many people involved in guardianship matters require support to effectively participate in proceedings, and legal representation to ensure access to justice. The provision of representation at first instance hearings is also likely to ensure efficient use of court or tribunal resources and reduce the number of appeals.²⁴³

We have been told that in some jurisdictions, such as Victoria and Queensland, limited legal representation for first instance hearings may be available either through legal aid or community legal centres. However, due to resource constraints, legal assistance for these types of civil matters is severely limited and frequently unable to meet demand.²⁴⁴

Additional safeguards for NDIS participants

Some jurisdictions have reported increases in the number of applications for new guardianship and administration appointments related to the NDIS.²⁴⁵ Additional safeguards may be needed around guardianship and administration applications for NDIS participants initiated by NDIS service providers. For example, it has been suggested that there could be an additional step before the submission of an application to a tribunal, such as a requirement to liaise with the NDIA or NDIS Quality and Safeguards Commission.²⁴⁶ Alternatively, the Royal Commission is interested in whether service providers should not be allowed to seek or be appointed as guardians or administrators.

Monitoring and oversight of restrictive practices

The Royal Commission has been told that use of restrictive practices on people subject to guardianship and administration requires further investigation. An analysis of the role of Australian guardianship laws in authorising restrictive practices for people with cognitive disability found inconsistencies across jurisdictions. It concluded that guardianship may not be an appropriate system to reduce reliance on restrictive practices.²⁴⁷

Concern has been raised that, without a consistent framework for the use of restrictive practices across all service sectors, guardianship has become a default means of authorising restrictive practices on people with impaired decision-making capacity. For example, the Northern Territory Office of the Public Guardian highlighted that the *Guardianship of Adults Act 2016* (NT) does not provide for authorising and monitoring of restrictive practices. In comparison, the *NDIS Authorisations Act 2019* (NT) establishes a restrictive practice framework for NDIS service providers and participants, including the authorisation of restrictive practices.²⁴⁸

Advocates have also advised that there is often more pressure on services to seek guardianship orders over individuals in institutional settings, such as group homes, to ensure ‘compliance’ with guidelines for using restrictive practices.²⁴⁹

Queensland and Tasmania have embedded frameworks within their guardianship laws to authorise restrictive practices in certain circumstances.²⁵⁰ In both states, safeguards include criteria for consent of restrictive practices, time limits, and regular review by tribunals.²⁵¹

Reform proposal 15: ‘Best practice’ safeguards in guardianship

States and territories should provide adequate safeguards in relation to guardianship and administration. This may require reform to include:

- access to alternative dispute mechanisms for people involved in guardianship matters. This may be achieved by granting Public Guardians or Public Advocates broad mediation functions
- improvements to monitoring and review, such as through the introduction of monitors and a registration system or further resourcing for existing oversight mechanisms
- enhanced investigation powers for Public Guardians and Public Advocates in cases of suspected abuse, neglect or exploitation
- the introduction of offence and compensation provisions in legislation
- mandatory independent legal representation for all adults who are the subject of guardianship and administration orders
- the NDIA and the NDIS Quality and Safeguards Commission taking a greater role in oversight of NDIS service providers that initiate guardianship and administration applications.

Discussion questions

1. Are the safeguards above the right ones within administration and guardianship? Are any safeguards missing?
2. Are there any unintended consequences or barriers to implementation we need to consider?

Reform proposal 16: Safeguards for restrictive practices within guardianship

If states and territories seek to authorise restrictive practices within the guardianship system, robust safeguards should be included in legislation to ensure appropriate oversight and monitoring. Safeguards should enable improvements in practice, including reducing and eliminating the use of restrictive practices.

Discussion questions

1. What safeguards for restrictive practices are required within guardianship?

Reforms for cultural safety

First Nations people under guardianship have told the Royal Commission about being denied the right to culture, to access Country, and to benefit from kinship relationships.²⁵² Self-determination is a cornerstone of individual and collective First Nations rights. Embedded in this is the right of First Nations people with disability to free, prior and informed consent to developments that affect them.

Research from Western Australia describes language barriers and a lack of cultural relevance in the State's guardianship system.²⁵³ Research from Queensland noted mistrust and suspicion of guardianship and administration systems; a cultural incongruence between Indigenous and Western worldviews on decision-making; and cultural bias in systems designed to assess cognitive and decision-making capacity.²⁵⁴

There is also concern at the overrepresentation of First Nations people with disability under guardianship orders and the comparative underrepresentation of First Nations people acting as guardians.²⁵⁵

In the Northern Territory, approximately 77 per cent of represented people with the Office of the Public Guardian involvement identify as First Nations.²⁵⁶ First Nations people represent just over 30 per cent of the Northern Territory population but are three times more likely than non-Indigenous people to have a guardianship order in place.²⁵⁷

The New South Wales Law Reform Commission considered that formal supported decision-making may be more culturally appropriate for First Nations people than substitute decision-making.²⁵⁸ It included special provision for First Nations people in its recommended framework for assisted decision-making, including requirements to:

- consider the specific circumstances of First Nations people and the systemic disadvantage they experience²⁵⁹

-
- have regard to regional cultural differences within jurisdictions, and cultural or linguistic factors specific to First Nations people when determining the decision-making ability of a First Nations person²⁶⁰
 - consider kinship systems customary laws when defining ‘relative’ and ‘spouse’.²⁶¹

Reform proposal 17: Reforms for cultural safety

States and territories should reform their guardianship and administration system to better provide cultural safety for First Nations people. This should include requirements on tribunal members to:

- consider the specific circumstances of First Nations people and the systemic disadvantage they experience.
- have regard to regional cultural differences within jurisdictions, and cultural or linguistic factors specific to First Nations people when determining the decision-making ability of a First Nations person.
- consider kinship and customary understandings of concepts like ‘relative’ and ‘spouse’.

Discussion questions

1. How else can the cultural safety of guardianship and administration systems be improved? Do you agree with the proposed requirements on tribunal members listed above?
2. Are there any unintended consequences or barriers to implementation we need to consider?

Transition points

Transitioning into guardianship

The Royal Commission is examining how certain transitions in people’s lives can give rise to situations where people with disability experience violence, abuse, neglect and exploitation. We are interested in whether there are certain pathways to guardianship, for example from some schools, psychiatric facilities, service settings, or aged care facilities.

In the United States, a national evidence base suggests a school-to-guardianship ‘pipeline’ whereby schools actively encourage parents to seek guardianship of their children with cognitive disability.²⁶²

Research commissioned by the Royal Commission found that an ‘over-protective’ approach by family members and disability workers often denied young people with cognitive disability the right to make decisions for themselves and develop important life skills.²⁶³

We have been told of the need for greater education on substitute decision-making for young people with disability, formal decision makers, family and friends, and health professionals.²⁶⁴ We have also heard there is a need for more independent advocates to work with and inform children and young people with disability about planning processes and available supports.²⁶⁵

The introduction of the NDIS may also be a factor in people of any age being appointed a guardian or administrator. A number of jurisdictions have reported increases in applications for new appointments directly related to the NDIS.²⁶⁶

However, there is a lack of research in Australia identifying key transition points that lead to guardianship and administration appointments.

Transitioning out of guardianship

People have described how guardianship and administration orders can be difficult to vary or revoke, despite existing review mechanisms. There is an onus on the person subject to an order to prove there is no longer a need for the order, and there is little guidance on the criteria for achieving this.

We have heard that an emphasis on skills development for people subject to guardianship and administration arrangements is necessary for people to transition ‘out’ of such arrangements. For example, some people with disability who have experienced exploitation have suggested that better support to self-manage funds and more practice with financial decision-making may have helped prevent some of the harm to which they were subjected.²⁶⁷

The pilot program in New South Wales found that people who were given opportunities to acquire skills and knowledge developed increased capabilities in financial decision-making, and expressed a desire to take on more financial responsibility and have administration orders revoked. Some participants were successful in having their orders removed.²⁶⁸

Developing decision-making skills has also been framed as a process of ‘risk enablement’.²⁶⁹ Limiting a person’s ability to make their own decisions and take risks can hinder them from learning from their actions and developing new strategies.²⁷⁰

Reform proposal 18: Transitions out of guardianship

States and territories should undertake efforts to reduce the number of people subject to guardianship and administration orders, and the length of time for which they are subject. These may include measures such as:

- A pilot program to divert a representative percentage of people from guardianship in each state or territory over the next 5 years, in order to foster innovation and develop an evidence base on how this can be done.
- A 'sunset clause' in each guardianship and administration order, after which time the order will lapse if there is not a successful application to renew it.
- A requirement on tribunal members to consider including a program of personalised skill-development in each guardianship or administration order.

Discussion questions

1. Do you agree that states and territories should take measures to decrease the numbers of people subject to guardianship and administration? What are the merits of the suggested measures listed above? What other measures would be effective?
2. Are there any unintended consequences or barriers to implementation we need to consider?

Education and training on supported decision-making

We have been told that a lack of awareness and recognition of the rights of people with disability has resulted in the over-utilisation of guardianship for people with disability.²⁷¹

With the exception of the Queensland Public Trustee pilot, there is limited evidence of how appointed guardians, administrators, attorneys or other formally recognised substitute decision-makers apply or understand supported decision-making in the context of their legally recognised roles.²⁷² In this pilot, professional staff with financial and other responsibilities for clients were provided with a decision-making framework. The pilot demonstrated a quantifiable shift in self-reported behaviour towards effective support practices.²⁷³

Victoria currently provides optional training sessions for newly appointed guardians and administrators. The Victorian Law Reform Commission also supported reforms to allow the Victorian Civil and Administrative Tribunal to order individuals to complete training as a condition of appointment as a guardian or administrator.²⁷⁴

Reform proposal 19: Education and training

The Australian Government and state and territory governments should ensure adequate education and training on human rights and supported decision-making is provided to tribunal members, legal representatives and other stakeholders involved in guardianship and administration matters.

Discussion questions

1. Do you agree with the proposal on education and training for stakeholders involved in guardianship and administration matters? Can you point to any existing good practice in education and training in this area?
2. Should education and training on supported decision-making be mandatory and supplemented with practice directions?

Data collection and public reporting

There is limited publicly available disaggregated data on people subject to guardianship and administration in Australia. For example, there is limited data on First Nations people under guardianship and administration.

There is also little publicly available information on circumstances that may lead to an order being made, or the nature and extent of any violence, abuse, neglect or exploitation experienced by people either before an order, or following an order. Some information about guardianship orders made in response to harm or a threat of harm is available for Queensland,²⁷⁵ Western Australia,²⁷⁶ and the Northern Territory.²⁷⁷

In June 2019, the Australian Guardianship and Administration Council released *Guidelines for Australian Tribunals* (the Guidelines) on maximising the participation of the person who is the subject of an application or review in guardianship or financial administration proceedings.²⁷⁸ Although these Guidelines are not binding, they are intended to provide a model of best practice and guidance to Tribunals.²⁷⁹

In developing the Guidelines, the Australian Guardianship and Administration Council noted the lack of available and reliable data on the participation rates of people subject to an order or review of a guardianship or administrative order.²⁸⁰ It proposed guidelines on the collection and public reporting of data including on:

- the participation rates of persons in hearings, broken down into in-person participation, hearings by video conference and hearings by telephone

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- the rate of appointment of representatives, broken down into the appointment of public representatives and private representatives
 - the number of appointments of representatives that are revoked, varied or reviewed
 - the rate of appointment of legal representatives, separate representatives and guardians ad litem to represent the person in proceedings.²⁸¹

Despite these guidelines, the collection and public reporting of this information remains limited across states and territories.

Reform proposal 20: Data collection and reporting

The Australian Guardianship and Administration Council should coordinate a consistent approach to the collection of data on guardianship and administration. This should include a requirement on state and territory tribunals to collect data on:

- the age, gender, First Nation status, ethnicity and location of people under guardianship and administration
- applications for guardianship and administration brought by service providers, and results of these
- participation of people with disability in guardianship and administration proceedings
- applications made in response to violence, abuse, neglect and exploitation
- the nature and extent of any violence, abuse, neglect and exploitation experienced by people under guardianship and administration orders
- the number of complaints, and outcomes of these, about guardians or administrators, including Public Guardians, Public Trustees or private guardians and trustees.

The Australian Guardianship and Administration Council should publish this data annually.

Discussion questions

1. Do you agree with that a consistent approach to the collection and reporting of data is needed? Should the Australian Guardianship and Administration Council be responsible for this? Are the categories of data listed above sufficient?
2. If not, what changes do you suggest and why?
3. Are there any unintended consequences or barriers to implementation we need to consider?

Appendix

Key concepts

Autonomy

In this paper, autonomy refers to a person's right and freedom to make their own decisions, to have control over their own lives, and to exercise choice.²⁸²

Autonomy is also centred on relationships, interdependence and social connectedness, reflecting the conditions in society which can result in dependence on others for support, such as exclusion, lack of accessibility and social marginalisation.²⁸³ Everyone is embedded in social relationships, and these influence our ability to make decisions about our lives.²⁸⁴

Dignity

Dignity, also referred to as 'human dignity' or 'inherent dignity', is an unconditional and inherent value that exists by virtue of being a person. Dignity is largely considered to be the 'ultimate foundation of all human rights and freedoms'.²⁸⁵

Upholding dignity can also be understood as a dynamic process. Governments, institutions and the community collectively have a role to play in creating the conditions where dignity is recognised and realised by ensuring all people a 'status of humanity'.²⁸⁶

Respect for dignity implies respect for the autonomy of a person and the right to not be devalued as a human being.²⁸⁷

Dignity of risk

'Dignity of risk' refers to the concept of affording a person the right and dignity to take reasonable risks.²⁸⁸ It is the idea that self-determination and the right to take reasonable risks are essential for a person's dignity and self-esteem and should therefore not be impeded.²⁸⁹ Dignity of risk is considered to be an essential part of autonomous decision-making by people with disability, particularly for people with cognitive disability.²⁹⁰

Capacity

'Legal capacity' provides the ability to hold rights and duties under the law, and to exercise those rights.²⁹¹ It is instrumental to legal personhood and allows a person's decisions and actions to be recognised and respected by the law. The realisation of autonomy depends on recognition of the ability of people with disability to exercise legal capacity. Legal capacity is also different from 'mental capacity'.²⁹² Mental capacity refers to a person's decision-making ability and skills, which can vary for each person over time for a range of reasons.²⁹³

Guardianship and administration

Guardianship and administration orders are legal decisions made by courts or tribunals that can allow a person to make decisions on another person's behalf.

Guardianship orders may cover decisions about a range of personal matters, including where a person lives, services, health care and other day-to-day matters. Administration or financial management orders authorise decisions about financial matters only.

A guardian or administrator may be a partner, family member or friend of a person with disability, or someone else who has a connection with the person.²⁹⁴ As a last resort, a public official may be appointed as a guardian or administrator. These officials have a range of different names in states and territories.²⁹⁵ In this paper, we refer to them as 'Public Guardians' and 'Public Trustees'.

Rights, will and preference

The concepts of 'rights', 'will' and 'preference' are generally expressed together as principles for guiding support in the exercise of legal capacity and decisions. 'Rights' refers to all human rights and fundamental freedoms; 'will' refers to longer term goals and value; and 'preferences' refers to more immediate choices such as day to day activities.²⁹⁶

Substitute decision-making

Substitute decision-making refers to a range of processes and regimes that involve a person making decisions on another person's behalf, where legal capacity is removed from a person. A substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against their will. Decisions can be based on what is believed to be in the 'best interests' of the person concerned, instead of the person's own will and preferences.²⁹⁷

Supported decision-making

Supported decision-making is about giving effect to the will and preferences of a person requiring decision-making support. It refers to a range of processes and approaches that assist people to exercise their autonomy and legal capacity by supporting them to make decisions about their own lives.

In this paper we adopt the term 'supported decision-making' to describe both the practical process and its implementation via policies and formal frameworks.

Endnotes

- 1 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019 (c).
- 2 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (a).
- 3 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, (h).
- 4 *Letters Patent* (Cth), 4 April 2019 amended 13 September 2019, recitals.
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- 7 *UN Convention on the Rights of Persons with Disabilities*, preamble, para (n).
- 8 *UN Convention on the Rights of Persons with Disabilities*, art 3(a).
- 9 United Nations General Assembly, Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007, United Nations, Treaty Series vol.999 p.3 (entered into force 3 May 2008) art 12(3).
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- 11 Committee on the Rights of Persons with Disabilities, *General Comment no. 1 (2014) Article 12: Equal recognition before the law*, CRPD/C/GC/1, (11 April 2014), [17].
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- 16 Public hearing 3: The experience of living in a group home for people with disability; Public hearing 4: Health care and services for people with cognitive disability; Public hearing 6: Psychotropic medication, behaviour support and behaviours of concern; Public hearing 8: The experiences of First Nations people with disability and their families in contact with child protection systems; Public hearing 11: The experiences of people with cognitive disability in the criminal justice system; Public hearing 12: The experiences of people with disability, in the context of the Australian Government's approach to the COVID-19 vaccine rollout; Public hearing 13: Preventing and responding to violence, abuse, neglect and exploitation in disability services (a Case Study); Public hearing 14: Preventing and responding to violence, abuse, neglect and exploitation in disability services (South Australia); Public hearing 15: Satellite hearing: Criminal justice and the NDIS; Public hearing 16: First Nations children with disability in out-of-home care; Public hearing 17: The experience of women and girls with disability with a particular focus on family, domestic and violence; Public hearing 18: The human rights of people with disability and making the Convention on the Rights of Persons with Disabilities a reality in Australian law, policies and practices; Public hearing 20: Preventing and responding to violence, abuse, neglect and exploitation in disability services (two case studies).
- 17 See for example: Transcript, Sally Robinson, Public hearing 3, 3 December 2019, P-106 [20-26]; Transcript, Anne Gale, Public hearing 14, 9 June 2021, P-226 [1-19]; Transcript, Claire Robbs, Public hearing 20, 14 December 2021, P-567 [8-24].
- 18 See for example: Name withheld, Submission, 11 February 2020; Name withheld, Submission, 20 December 2019; Name withheld, Submission, 11 May 2020.
- 19 Oliva Davis, Submission, 9 January 2020; Chris Fletcher, Submission, 17 February 2020; Name withheld, Submission, 20 December 2019; Fiona Coglin, Submission, 24 June 2020; Peter Buckland, Submission, 13 March 2020.

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- 20 Julie Bury, Submission, 15 November 2019; Name withheld, Submission, 20 December 2019.
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