ACT Law Reform Advisory Council

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<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACAT</td>
<td>The ACT Civil and Administrative Tribunal</td>
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<td>ACT</td>
<td>Australian Capital Territory</td>
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<td>ADACAS</td>
<td>ACT Disability, Aged, Carer Advocacy Service</td>
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<td>ALRC</td>
<td>Australian Law Reform Commission</td>
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<td>Health Directions Act</td>
<td>Medical Treatment (Health Directions) Act 2006 (ACT)</td>
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<td>Human Rights Act</td>
<td>Human Rights Act 2004 (ACT)</td>
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<td>Mental Health Act</td>
<td>Mental Health Act 2015 (ACT)</td>
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<td>NDIS</td>
<td>National Disability Insurance Scheme</td>
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<td>NDIS Act</td>
<td>National Disability Insurance Scheme Act 2013 (Cth)</td>
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<td>QLRC</td>
<td>Queensland Law Reform Commission</td>
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<td>The Council</td>
<td>ACT Law Reform Advisory Council</td>
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<tr>
<td>The Guardianship Act</td>
<td>Guardianship and Management of Property Act 1991 (ACT)</td>
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<td>UN Convention</td>
<td>United Nations Convention on the Rights of Persons with Disability</td>
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<td>VLRC</td>
<td>Victorian Law Reform Commission</td>
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PART 1: INTRODUCTION

1.1 Terms of Reference

The ACT Attorney-General, Simon Corbell MLA, requested the ACT Law Reform Advisory Council (the Council) to undertake an inquiry into the terms and operation of the ACT’s Guardianship and Management of Property Act 1991 (the Guardianship Act) to ensure that the Act reflects best practice in guardianship law relating to adults. The Terms of Reference are as follows:

The Law Reform Advisory Council is asked to inquire into the terms and operation of the Guardianship and Management of Property Act 1991, to ensure that the Act reflects best practice in guardianship law relating to adults. The review does not include consideration of guardianship of children which is primarily a parental responsibility.

In making any recommendations, the Council should have regard to the General Principles established in the United Nations UN Convention on the Rights of Persons with Disabilities focusing on the principle of respect for individual autonomy and dignity of persons, which is reflected in supported decision making frameworks.

The review will include consideration of:

1. The impact of the United Nations UN Convention on the Rights of Persons with Disabilities and other international human rights instruments, on principles for guardianship and management of property in the A.C.T;
2. The Act’s consistency with other relevant ACT legislation, in particular the Human Rights Act 2004, the Mental Health (Treatment and Care) Act 1994; the Powers of Attorney Act 2006 and the Disability Services Act 1991; and
3. Current policy trends in the area of guardianship and substitute decision making in the ACT.

The Council was originally scheduled to report its findings to the Attorney-General by 30 September 2015 and the Attorney-General provided an extension to accommodate the scope of the work. This Report was provided to the Attorney-General on 29 July 2016.


1.2 Conduct of the inquiry

The Australian Law Reform Commission (ALRC) conducted a review of equal recognition before the law and legal capacity for people with disability in the Commonwealth jurisdiction in 2013-2014. The ALRC’s inquiry reviewed and responded to other Australian reviews of guardianship laws, researched international developments in other jurisdictions, and conducted an extensive consultation process. The ALRC’s Final Report was published at the very beginning of the Council’s inquiry. The Final Report provided a set of principles and guidelines that reflect the current state and future direction of an approach to guardianship that is compatible with Australia’s international obligations under the UN Convention on the Rights of Persons with Disabilities (UN Convention). The Council therefore resolved that the ALRC’s Final Report, and the National Principles and Guidelines, would be the framework within which it would conduct its inquiry.

The Council used the National Principles and Guidelines as the basis for its public consultations. It sought people’s accounts of their experience with existing guardianship arrangements and their views about how the National Principles and Guidelines might work in the ACT, and facilitated this with a public response booklet in hard copy, soft copy and online. The Council worked with the ACT Disability, Aged, Carer Advocacy Service (ADACAS) to develop an Easy English consultation document called Making Decisions about Your Life, and made a brief video, on its website, to explain the nature and process of the inquiry.

Views on the National Principles and Guidelines were sought from people with impaired decision making ability, guardians, carers, family members, disability support providers, service providers and agencies, and businesses

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who have dealings with people with impaired decision making ability. As well, the Council also invited people who had participated in supported decision making to share their stories of this experience.

The Council met and corresponded with individuals and organisations interested in the reference. It held consultations with a range of ACT and Commonwealth Government agencies, individual carers and groups of carers, consumer advocacy groups, people involved with aged care, health professionals, business organisations, individual experts, the ACT Civil and Administrative Tribunal (ACAT), the Public Guardian, the Office of the Public Advocate, and the Public Trustee. The Council received 21 written submissions; a list of those who made a submission and agreed to be identified is in Appendix 1.

The Council is very grateful to all who participated in the forums and meetings, and who took the trouble to prepare a written submission; its work and this Report have been enriched by those experiences and views.

### 1.3 Acknowledgements

The Council was established by the ACT Attorney-General, the Hon Simon Corbell MLA, to provide expert advice and recommendations to the Attorney-General. The Council operates as a collaborative undertaking between the ACT Government and the ANU College of Law at the Australian National University, which together provide the funds, resources, infrastructure and staff necessary for the Council’s operation. The Council is supported by a part-time Executive Officer located at the ANU College of Law.

Members of the Council are appointed by the Attorney-General for a period of up to three years, on the basis of their relevant and varied experience and expertise. Members contribute to the work of the Council on a voluntary basis.

Members of the Council at the time of reporting on the Guardianship Act review were:

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<th>Name</th>
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<tr>
<td>Dr Lorana Bartels</td>
<td>Mr Stuart Pilkinton SC</td>
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<tr>
<td>Justice John Burns</td>
<td>Professor Simon Rice, OAM (Chair)</td>
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<tr>
<td>Mr David Heckendorf</td>
<td>Ms Louise Taylor</td>
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<td>Mr Martin Hockridge</td>
<td>Chief Magistrate Lorraine Walker</td>
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<td>Mr John Kalokerinos</td>
<td>Dr Helen Watchirs, OAM</td>
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<td>Assistant Commissioner Rudi Lammers, APM</td>
<td>Ms Heidi Yates</td>
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The conduct of the review and the terms of the Final Report were overseen by the Chair of the Council, Professor Simon Rice and the Acting Chair Associate Professor Tony Foley, who was appointed by the Minister during the Chair’s period of leave.

Ms Fiona Tito Wheatland was the Council Executive Officer responsible for the Guardianship Review and is principally responsible for drafting this Report.

Ms Olivia Kelly, Ms Christina Karolis, Mr Nelson Mendonca and Ms Elizabeth Abbott were ANU College of Law student interns with the Council who conducted research and worked on the review, and their work has informed this Report. Mr Mendonca also provided additional assistance with research after his internship was completed, and this research contributed significantly to a number of parts of this Report.
1.4 The scope of this Report

It was clear from the public consultations that in the relatively short time available to report on the inquiry, the Council would not be able to address in detail all of the changes necessary to give full effect to the UN Convention in the ACT. The Council’s brief is limited to law reform in relation to substitute decision making. However, the practical implications of legislation, and whether legislation is necessarily the most effective way of achieving the intended policy aim of compliance with the UN Convention, are questions that have to be addressed in this Report. While some legislative change is likely to be required, it is apparent that, even without legislative change, many people who are administering and acting under the current Act are already giving effect to the supported decision making principles of the UN Convention. In some areas of activity, the law needs reform to catch up with and better reflect practices. However, in other areas of activity, the law will lead the change in practice.

Pilot programs and other developmental activities are underway and continuing in the ACT and around Australia. These will provide further evidence and information on which to develop the details of reform that will be necessary to ensure UN Convention compatibility. However, enough is already known to commence the legislative reform process; in this Report, the Council addresses fundamental questions of law reform, and maps out the further work that is necessary to fully implement the supported decision making requirements of the UN Convention.

The Report does not include recommendations relating to a number of areas of law that will require examination for compliance with the UN Convention. These are the subject of separate recommendations in Part 10 below (Recommendations 11 and 12).
PART 2: EXECUTIVE SUMMARY AND RECOMMENDATIONS

The Council makes a number of recommendations. They are organised into four groups:

- policy, principles and legislation;
- a new ACT Decision making Framework;
- implementation of an ACT Decision making Framework; and
- related matters.

A. Policy, Principles and Legislation

Changing the basis for decision making in the ACT to comply with the UN Convention on the Rights of Persons with Disabilities

The purpose expressed in the UN Convention on the Rights of Persons with Disabilities is:

to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities; and to promote respect for their inherent dignity.

The ACT Human Rights Act recognises similar rights and requires that “Territory laws” be interpreted in a way that is compatible with human rights.

Under Article 12 of the UN Convention and the ACT’s Human Rights Act, all people with disabilities have a right to recognition before the law and to enjoy legal capacity on an equal basis with everyone else. These provisions mean that adults with impaired decision making ability have a right to exercise their legal capacity through making decisions with or without support, based upon their will, preferences and rights, subject to appropriate safeguards. This is based upon:

- a presumption of legal capacity;
- a recognition of their will, preferences and rights as the basis for decision making; and
- an acknowledgement that support must be provided to maximise the exercise of their ability whenever possible.

‘Substitute’ decision making is currently used in the Guardianship Act and other ACT legislation relating to people with impaired decision making ability. This provides for a ‘substitute’ decision to be made on behalf of a person with impaired decision making ability, based on the substitute decision-maker’s view about what is in that person’s ‘best interests’. To comply with the UN Convention, all relevant legislation, policy and procedure for people with impaired decision making ability must move to ‘supported decision making’, based on the will, preferences and rights of that person.

Recommendation 1:

The Council recommends that the ACT Government adopt a decision making paradigm for people in the ACT with impaired decision making ability that replaces a ‘best interests’-based substitute decision making model with a ‘will, preferences and rights’-based supported decision making model and that this model be reflected in legislation.

Law reform options

The Council’s preferred law reform option is the enactment of a new overarching Supported Decision making Act, which would apply to all relevant civil legislation in the ACT and consequential amendment to other legislation. This model has recently been adopted in the Irish Republic in its Assisted Decision making (Capacity) Act 2015.

If this option is not accepted, the Council’s second preference is for the insertion in all relevant ACT legislation of a standardised model of supported decision making, consistent with the recommended policy change.
If neither of these two options is accepted, the Council proposes the insertion in the Guardianship Act of a statutory model of supported decision making consistent with the change of policy and principles recommended above. However, this last option will leave a number of other significant Acts non-compliant with the UN Convention and with the ACT’s Human Rights Act.

With all these options, there are likely to be consequential amendments involving other legislation.

**Recommendation 2:**

The Council recommends that legislation to implement the new ‘will, preferences and rights’-based supported ACT Decision making Framework be prepared for public consultation, using one of the following options in order of preference:

1. A single Act providing for the overarching reform of the law relating to people who require or may require assistance in exercising their decision making ability to mandate the use of the ‘will, preferences and rights’-based supported decision making framework; or

2. The use of a ‘will, preferences and rights’-based supported decision making framework be independently inserted in all existing legislation that currently provides for substitute decision making for people who require or may require assistance in exercising their decision making ability; or

3. A ‘will, preferences and rights’-based supported decision making framework for people who require or may require assistance in exercising their decision making ability, be inserted in the Guardianship and Management of Property Act 1991 in place of the current ‘best interest’-based substitute decision making provisions.

**The Principles for Reform**

A simple, concise statement of principles should be adopted which affirms and provides the basis for this paradigm shift. The Council recommends the broad framing principles for reform of laws relating to people with disabilities recommended by the Australian Law Reform Commission in its Final Report, Equality, Capacity and Disability in Commonwealth Laws, for this purpose. These principles are: dignity, equality, autonomy, inclusion and participation, and accountability.

In the context of reform of decision making arrangements for people with impaired decision making ability, the Council’s consultations also showed broad support for the Australian Law Reform Commission’s National Decision making Principles. The Council believes that these principles provide a sound basis for reform of decision making laws in the ACT.

**Recommendation 3:**

The Council recommends that the ACT’s reform of law and policy relating to decision making arrangements for people with impaired decision making ability be based upon the Australian Law Reform Commission’s four National Decision making Principles:

1. Principle 1: All adults have an equal right to make decisions that affect their lives and to have those decisions respected;
2. Principle 2: People 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;
3. Principle 3: The will, preferences and rights of persons who may require decision making support must direct decisions that affect their lives; and
4. Principle 4: There must be appropriate and effective safeguards for people who may require decision making support, including to prevent abuse and undue influence.

**Decision making guiding principles**

The Australian Law Reform Commission also developed three sets of guidelines to underpin its National Decision making Principles. These were its Support; Wills, Preferences and Rights; and Safeguards Guidelines. These Guidelines provide strong philosophical and practical guidance for new legislation, policy and procedures. They also
provide a useful basis for a nationally consistent approach to decision making for people with impaired decision making ability. The Guidelines received strong community support in submissions to the Council.

**Recommendation 4:**

The Council recommends that the development of legislation, policy and procedures to implement the new ACT Decision making Framework be informed by the principles in the Australian Law Reform Commission’s Guidelines on Support; Wills, Preferences and Right; and Safeguards.

**B. A new ACT Decision making Framework**

**Decision making – support and representation**

The Australian Law Reform Commission recommended that support be made available for people who needed assistance to exercise their decision making ability in the form of supported decision making. In cases where this was not possible, the Australian Law Reform Commission proposed there be representative decision making. In both circumstances, the decision making would be directed by the will, preferences and rights of the decision-maker.

The Council was persuaded by the work of other law reform agencies in Australia and overseas that there was also a place for co-decision making as an additional form of supported decision making in appropriate circumstances. A new decision making framework based on these three forms is recommended.

**Recommendation 5:**

The Council recommends that the ACT’s new framework for supported decision making provide for three forms of assisted decision making:

5.1 **Supported decision making:** The decision making framework requires and provides support for decision making based upon the will, preferences and rights of someone whose decision making ability is impaired.

5.2 **Co-decision making:** Where impaired decision making ability makes the exercise of decision making ability with support difficult, additional support shall be provided to allow the person to properly exercise their decision making ability.

5.3 **Representative decision making:** Where it is not possible to provide sufficient support for a specific decision by a person with impaired decision making ability, any method chosen to make that decision must be representative of the will and preferences of the person with impaired decision making ability, as well as being consistent with their rights.

**Supported Decision making**

The legislation needs to reflect a flexible decision making process for people with impaired decision making ability, in recognition that their ability will vary over time and with the nature of decisions. In addition, the availability of support will also vary over time. The first and preferred step in the ACT Decision making Framework is to ensure the availability of a range of supports, where someone wants or needs assistance to exercise their decision making ability, based upon their will, preferences and rights.

**Recommendation 6:**

The Council recommends that the ACT Decision making Framework be based upon the provision of support for decision making, where someone wants or needs support to exercise their decision making ability. This support must be based upon the will, preferences and rights of someone whose decision making ability is impaired. Such support may include any actions which provide support for a decision-maker to exercise their decision making ability, including:

(a) reasonable accommodation; and

(b) the provision of various means of informal and formal support for decision making, with reviewable statutory guidelines about how such support can best be provided, without the prescription of a specific model.
Co-Decision making

Where specific decisions could carry an unreasonable risk of substantial harm for a decision-maker acting alone, but where, with sufficient support, the person can still exercise their decision making ability, the Council proposes that a co-decision making option be available in place of supported decision making. This model exists under the Irish Republic’s Assisted Decision making (Capacity) Act 2015. The model was also recommended for certain decision making situations by the Victorian Law Reform Commission in its 2012 review of guardianship laws. Under this option, decisions are negotiated and agreed jointly by the decision-maker and the co-decision maker. The decision making is guided by the will, preferences and rights of the decision-maker. If the decision-maker and co-decision-maker are unable to agree, provision can be made for an appropriate independent person or agency to work with them, to support their relationship and assist in reaching a joint decision.

Recommendation 7:

The Council recommends the availability of co-decision making as a distinctive form of supported decision making where someone requires a higher level of support to exercise their decision making ability in relation to specific decisions, particularly those decisions which may involve risk of substantial harm to the decision-maker which risk cannot reasonably be ameliorated through risk reduction strategies.

Representative Decision making

The Australian Law Reform Commission model also provides for ‘will, preferences and rights’-based representative decision making as a last resort when neither supported or co-decision making are able to provide sufficient support for the person to exercise their own decision making ability. A representative decision-maker can be a person chosen by the decision-maker to represent them with appropriate safeguards, or, a person formally appointed by the ACT Civil and Administrative Tribunal. In most cases, representatives would need to demonstrate that they have sought to support the decision-maker to participate in decision making to the greatest extent possible before they acted as the representative decision-maker and this would need to be recorded appropriately.

Recommendation 8:

8.1 Where it is not possible to provide sufficient support for someone to exercise their decision making ability either as a supported or co-decision-maker, and a representative is appointed either by the person or by the ACT Civil and Administrative Tribunal, any decision made by a representative must be representative of the will and preferences of the person with impaired decision making ability, as well as being consistent with their rights.

8.2 Appointment to act as a formal representative decision-maker for another person shall be subject to application to the ACT Civil and Administrative Tribunal, to determine that options of supported and co-decision making have first been exhausted.

8.3 Where the need for a representative decision occurs in an emergency, there should be a temporary power for a person previously nominated by the person with impaired decision making ability to act as their representative, or alternatively a person who has authority under the existing Health Attorney provisions to make representative decisions for the person, based on their will, preferences and rights. Where the decision-maker does not recover their decision making ability in the short term, then approval must be sought for appointment as a representative decision-maker in accordance with the terms of 8.1 and 8.2 above.

Determining and recording a person’s will and preferences

Respecting the will, preferences and rights of people who require support to exercise their decision making ability is a central feature of the new ACT Decision making Framework. Determining the will and preferences of a person with impaired decision making ability may require a new set of administrative processes. The determination will often be made through discussion and engagement between the decision-maker and their supporters, family, carers and service providers at the time of decision making. This is necessarily a staged deliberative process. Such a process of discussion and engagement is not possible for instance where a person is unconscious or otherwise unable to express their will and preferences. Some other process for determining the person’s will and preferences is then required.
There are a limited number of ways that a person can record their wishes and preferences under the current legislation in the ACT. Existing provisions, particularly in relation to medical decision making, are complex and, at times, conflicting. There is no central administrative arrangement to record the will and preferences of a person for subsequent access when needed. A requirement to register any such expression of will and preferences could also allow an oversight or review body to have point-in-time evidence of the will, preferences and rights of the decision-maker.

**Recommendation 9:**

9.1 The new ACT Decision making Framework should provide the opportunity and a mechanism for people to formally record their will and preferences about specific issues, in a way that can be readily accessed when needed. Existing mechanisms such as advance care directions or consents and agreements under the Mental Health Act 2015 provide potential models. Extending such options to other areas of decision making should be explored and developed for affected persons to be able to formally record their will and preferences about specific issues.

9.2 Where existing Enduring Powers of Attorney are in operation, a transition period should be set to provide opportunity for such agreements to be registered or renewed so as to remain operative.

The first necessary step to ensure decision making arrangements can be safeguarded under the proposed ACT Decision making Framework is to know they exist. At the moment, there is no scrutiny of substitute decision making under the enduring power of attorney provisions of the Powers of Attorney Act 2006 (ACT), but the powers exercised may be as significant as those exercised under the Guardianship Act. In future, where someone wishes to appoint another person as a supporter or a representative, a register will be required to ensure that these wishes are able to be known if and when needed.

**Recommendation 10:**

10.1 The Council proposes that in the transition period, all existing substitute decision making arrangements be brought under a common registration and monitoring regime, to facilitate the transition to the new ACT Decision making Framework.

10.2 Where a person wishes to nominate a supporter or representative for situations where they may need support for decision making in the future, administrative processes for the registration of all such agreements should be developed as part of the transition arrangements. Registration will facilitate the formal recognition of people’s will and preferences, and provide administrative capacity to monitor and review such arrangements to ensure the protection of the rights of decision-makers with impaired decision making ability.

**C. Implementation of an ACT Decision making Framework**

In addition to the need for legislation change, the paradigm shift set out in the recommendations above will require consequent cultural and procedural change. The new ACT Decision making Framework will affect many people, including existing guardians and managers, people subject to guardianship, carers and families, and service providers, as well as the broader community. The Council considers that a transition period, where elements of the legislative part of the Framework are implemented, be accompanied by appropriate education and community information. These changes are likely to require time and resources to develop and implement.
Building community capacity

Significant community capacity building will be required to move to the new ACT Decision making Framework. This will include:

a. the development and provision of explanatory information and education programs to promote supported decision making skills and change decision making culture across the community;

b. support for relational changes necessary to allow greater decision making by those who are currently under a substituted decision making arrangement;

c. observation of and learning from pilot supported decision making processes;

d. development of ways of assessing the supports someone may need to exercise their decision making ability;

e. assistance for people with impaired decision making abilities to become ‘decision ready’ and learn specific decision making skills for those decisions they see as important to their lives;

f. administrative mechanisms to help facilitate the making and implementation of supported decisions, including guidelines for the various roles in a supported decision making environment;

g. development of appropriate registration processes, so that people can record their will and preferences and any formal arrangements they want to operate to support their decision making; and

h. development and implementation of appropriate monitoring and oversight mechanisms, where these are necessary.

Recommendation 11:

The Council recommends that there be a transition period for implementation of the new ACT Decision making Framework, in acknowledgement of the need for considerable community capacity building, the development and delivery of educational and information programs, and the necessary review of existing administrative arrangements to occur.

Ensuring oversight and review

The implementation of a new paradigm in relation to decision making may involve difficulties for some people in making that transition. As noted above, there will be a significant need for capacity building for both decision-makers, supporters, family, carers and service providers. During the transition period, there must be a focus on skills development and education to encourage a willingness to ‘try out’ new ways of behaving until affected people feel comfortable in the new paradigm. To ensure that decision-makers who need support are able to use their own decision making ability, there will need to be resources provided from which to obtain appropriate advice. At times, intervention may be required to ensure the will, preferences and rights of the person requiring decision making support are being respected and acted upon. Such oversight and review functions should lie with the Human Rights Commission and/or the ACT Civil and Administrative Tribunal.

Recommendation 12:

12.1 Where a person who needs support to exercise their decision making ability considers that their will, preferences and rights are not being respected, a right to seek advice and intervention from the Human Rights Commission or where necessary, review by the ACT Civil and Administrative Tribunal should be established. Grounds for intervention or review would include breaches of the Guidance Principles proposed in Recommendation 13, including for example:

(a) a supporter’s unreasonably limited expectations of a decision-maker’s ability, resulting in the decision-maker having little or no opportunity to exercise their decision making ability to make their own choices;

(b) unreasonable curtailment of risk;

(c) conflicts of interest;

(d) undue influence;

(d) competing rights between the supported decision-maker and their supporters;
Developing guidelines for supporters, representatives and others

The new ACT Decision making Framework requires supporters, representatives and others who have been acting under the ‘best interests’ substitute decision making paradigm to operate very differently in supported decision making. This will involve a significant shift in the power dynamic within close and sometimes complex relationships. To facilitate this, statutory non-statutory guidance consistent with the ‘will, rights and preferences’ supported decision making paradigm will need to be developed and adopted during the transition period. The development of this guidance will need to take account of the results of supported decision making pilots conducted around Australia, as well as changes to decision making as a consequence of the implementation of the National Disability Insurance Scheme (NDIS).

**Recommendation 13:**
The proposed ACT Decision making Framework should include guidance materials (both directive and informative) for supporters, representatives and others to guide their behaviour appropriately in supporting a person to exercise their decision making ability.

**D. Related matters**

The UN Convention requires that people with disabilities have the right to recognition as ‘persons before the law’ in all circumstances, and that they enjoy legal capacity on an equal basis with all other people. While the Council’s Terms of Reference focus on the current Guardianship Act and supported decision making, it is clear that the requirement for equal recognition need to be evident in other ACT legislation.

**Amendment of legislation that relates to legal capacity**

The Council was made aware through its research for this reference that the terms ‘legal capacity’ and ‘mental capacity’ are used (sometimes interchangeably) in many pieces of legislation in the ACT, in ways which do not comply with the Convention’s intention. There is significant variation, ambiguity and confusion about what is constituted by ‘capacity’ in these various provisions. In some instances, ‘capacity’ refers to legal personhood; in other instances, ‘capacity’ is concerned with decision making ability, or ability to do some other task specified in the legislation. In order to comply with the spirit of the UN Convention, the ACT legislation needs to be reviewed to ensure consistency in the treatment of all people as equal before the law. Any legislative limitations on this equality must be framed in a way which is consistent with a person’s ability to carry out the specific functions under the relevant legislation (with such support as necessary, if that ability is impaired).

**Recommendation 14:**
The Council recommends that the Government undertake an audit of ACT legislation to identify where amendments are required to give effect to Article 12 of the UN Convention on the Rights of Persons with Disabilities to ensure that all people (including those with disabilities) are treated equally before the law and, where necessary, support is available to enable this to occur. Legislative language needs to be framed in terms of ‘ability with support’, rather than ‘capacity’ and ‘incapacity’. Whenever the terms ‘legal capacity’ or ‘mental capacity’ are used, or the word ‘capacity’ is used to indicate ‘legal capacity’ or ‘mental capacity’, the term ‘decision making ability’ may need to be used instead. Similarly, whenever the terms ‘legal incapacity’ or ‘mental incapacity’ are used, or the word ‘incapacity’ is used to indicate ‘legal incapacity’ or ‘mental incapacity’, the term ‘impaired decision making ability’ may need to be used instead.

**Future review of criminal justice legislation and practice**

The Council notes that there are implications for criminal justice practice and procedure in the UN Convention on the Rights of Persons with Disabilities that are outside the Council’s Terms of Reference and have not been considered.
There is likely to be strong public interest that criminal justice practice and procedure also made compliant with the principles of the UN Convention.

The Australian Law Reform Commission has made recommendations in this area. While the Council’s current recommendations do not address whether reform to the criminal justice system is necessary, a separate inquiry to consider this is warranted.

**Recommendation 15:**

The Council notes that there are implications for criminal justice practice and procedure in the UN Convention on the Rights of Persons with Disabilities that are outside the Council’s Terms of Reference and have not been considered. The Council recommends that consideration be given to the reform of the law in this area.

**Compulsory treatment, restraint and seclusion**

There are situations where a person’s decision making capacity is impaired and their actions are seen as likely to cause significant risk to self and/or others. In these situations, the imposition of force against that person’s will to protect that person and/or others from harm may be considered necessary. It is hoped that the context of supported decision making and new understandings of how to work with people with impaired decision making who may experience psycho-social difficulties will minimise situations where the imposition of such force will be necessary. However, where the use of force or compulsion is necessary, there need to be procedural guarantees to manage the use of force in any legislation (as amended). Any use of force in these circumstances should require the oversight of an external body, and in most cases, prior approval should be obtained from by a publicly accountable decision making body such as the ACT Civil and Administrative Tribunal.

The *Mental Health Act 2015* (ACT) deals with the imposition of force in the context of mental health involuntary detention and treatment orders which are regulated by statutory safeguards. In submissions to the Council, examples were given of the imposition of force occurring under guardianship arrangements not regulated by legislation, such as in aged care facilities, disability services and health services.

There is a need for careful consideration of the most effective ways of ensuring the protection of people with impaired decision making who are considered to be at risk of harming self or others and therefore potentially subject to the need for the imposition of force. The Council considers that further work is required to develop the most appropriate approach to such coercive or restrictive practices, including in circumstances of compulsory treatment, restraint, seclusion, mandatory living arrangements and other controls, which may be seen as breaching the rights of a person with impaired decision making ability.

**Recommendation 16:**

The Council considers that strong and consistent safeguards are required to regulate any restrictive or coercive practices applied to people with impaired decision making ability. While the Council is attracted to using a similar set of requirements as are set out in the *Mental Health Act 2015* (ACT), the Council recommends that a further review is needed to ensure a proper consideration of the complex issues raised by these questions.
PART 3: GUARDIANSHIP AND SUBSTITUTE DECISION MAKING IN THE ACT

Overview of this Part

The focus of the Council’s inquiry is the mechanism of guardianship, and so this Part begins with an account of the way in which the Guardianship and Management of Property Act 1991 (ACT) (the ‘Guardianship Act’) has developed and now operates.

The exercise of guardianship is, essentially, the making of decisions by the guardian as a substitute for the person under guardianship: that is to say ‘substitute decision making’. Other laws in the ACT make provision for substitute decision making and they are described at the end of this Part: the Powers of Attorney Act 2006 (Powers of Attorney Act), the Medical Treatment (Health Directions) Act 2006 (Health Directions Act), and the Mental Health Act 2015 (Mental Health Act).2

3.1 The Guardianship Act

3.1.1 Who is subject to guardianship in the ACT?

One question that needs to be considered is the number of people who may be affected by the reform of this and other substitute decision making legislation in the ACT. What becomes clear is that there are no comprehensive data available. There is more data available on guardianship in the ACT because these arrangements come after an order of the ACAT or from some other judicial body. However, because there is no requirement to register arrangements made elsewhere and under other mechanisms, like Enduring Powers of Attorney, the available information is far from complete. There is also some information available from ‘last resort’ appointments under the Public Advocate and on the review functions and last resort functions of the Public Trustee. Again these only provide a partial picture. The lack of a comprehensive record of these arrangements means that there is no protective oversight available, and, examples were provided to the Council where this has led to exploitation and harm to the protected person.

Data on the Guardianship work of ACAT

ACAT has taken on an increasingly active role in relation to reviewing guardianship orders made previously, consistent with the move away from plenary orders of unlimited duration.

Figure 13 provides details of the number of applications considered by ACAT over the past five years. Applications can include seeking orders to grant, vary or remove guardianship arrangements.

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2 This Act commenced on 1 March 2016, and replaced the Mental Health (Treatment and Care) Act 1994.
Notwithstanding that the number of applications lodged, have increased, the number of grants of new Guardianship orders has declined, as can be seen from Table 2

The most recent data on the underlying causes for why guardianship orders at ACAT are sought is in Figure 3 below. In submissions, there was some concern raised about the use of plenary orders in the ACT. It is understood that ACAT, through its own motion reviews, is reviewing the appropriateness of all plenary orders to see if such wide powers are necessary.

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4 See, eg, ACT Health, Submission 21, Appendix A, paragraph 5.
5 Comment by General President Crebbin ACAT at Guardianship and Financial Management Roundtable 21 May 2015.
Data on the Public Guardianship Function

The Public Trustee and Guardian acts as a Guardian of Last Resort, where ACAT considers that someone needs a guardian, but there is no other suitable person willing or able to fulfil this function. This role was undertaken by the Public Advocate until 1 April 2016, and data available relates to the Public Advocate. The numbers of people subject to these arrangements have varied over the past decade, as set out in Figure 4.

Figure 3: Conditions affecting people subject to applications for new Guardianship Orders - ACT 2014-2015 ACAT

- Dementia: 34%
- Mental Illness: 28%
- Intellectual Disability: 19%
- Acquired Brain Injury, including stroke: 19%

Figure 4: Number of people for whom Public Advocate acted as ‘Guardian of Last Resort’ over past ten years
While demographic data is not published each year for this group, in 2011-12, the Public Advocate’s Annual Report noted that 45% of these clients were female. Figure 5 shows their age distribution.

The number of people under the Guardian of last resort arrangements at any one time (shown in Figure 4 above) is a measure of the stock and flow of clients. Each year new appointments are made both to Private Guardians and to public guardians. The number of new ‘Guardian of Last Resort’ clients has declined since 2011-12.

The stock of public ‘Guardian of Last Resort’ clients is also affected by those who leave each year for various reasons. The following table provides data on the reasons people left ‘Guardianship of Last Resort’ arrangements, when this function sat with the Public Advocate.
<table>
<thead>
<tr>
<th></th>
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<td>Client deceased</td>
<td>11</td>
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<td>16</td>
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<tr>
<td>Client regained capacity</td>
<td>0</td>
<td>6</td>
<td>4</td>
<td>2</td>
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<td>No decisions made so PA requests cessation</td>
<td>15</td>
<td>5</td>
<td>13</td>
<td>33</td>
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<tr>
<td>Matter resolved so order no longer required</td>
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<td>16</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Client relocated to another jurisdiction</td>
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<td>3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Alternative guardian appointed</td>
<td>3</td>
<td>8</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
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<tr>
<td>Total</td>
<td>38</td>
<td>52</td>
<td>45</td>
<td>61</td>
</tr>
</tbody>
</table>

**Data on the Public Trustee of the ACT Financial Management Function under the Guardianship Act**

The Public Trustee fulfils a number of different roles in relation to the Guardianship Act. The Public Trustee acts as a financial manager of last resort under ACAT orders; as a Financial Manager when appointed under an enduring power of attorney which subsequently becomes operative; and as a regulatory supervisor of private guardians who have been given financial management responsibilities as well.

3.1.2 Overview of the current Guardianship Act

The Guardianship Act sets up a statutory regime applying to ‘decision-makers’ for ‘protected persons’.

A decision-maker is a person who ‘exercise[s] a function under [the] Act in relation to a person with impaired decision making ability’ (s 4(1)). People who exercise a function under the Act in relation to a person with impaired decision making ability are guardians appointed by ACAT to make decisions about a person’s health and welfare (Part 2 of the
Act), managers appointed by ACAT to make decisions about a person's financial matters or property (Part 2), health attorneys as defined by the Act (Part 2A), and attorneys appointed under an enduring power of attorney (Part 3).

A person with impaired decision making ability is a ‘protected person’ (s 4(1)), defined as a person whose ‘decision making ability is impaired because of a physical, mental, psychological or intellectual condition or state, whether or not the condition or state is a diagnosable illness’ (s 5). This definition is tied to the existence of a disability, which excludes (s 6A) a person who:

a. is eccentric; or
b. does or does not express a particular political or religious opinion; or
c. is of a particular sexual orientation or expresses a particular sexual preference; or
d. engages or has engaged in illegal or immoral conduct; or
e. takes or has taken drugs, including alcohol (but any effects of a drug may be taken into account).

As well as using the term ‘impaired decision making ability’, the Guardianship Act uses the term ‘impaired decision making capacity’ but only when referring to the exercise of a power of attorney, as defined by the Powers of Attorney Act 2006.

The Guardianship Act prescribes a set of decision making principles to be followed by the decision-maker (s 4(2)):

a. the protected person’s wishes, as far as they can be worked out, must be given effect to, unless making the decision in accordance with the wishes is likely to significantly adversely affect the protected person’s interests;
b. if giving effect to the protected person’s wishes is likely to significantly adversely affect the person’s interests—the decision-maker must give effect to the protected person’s wishes as far as possible without significantly adversely affecting the protected person’s interests;
c. if the protected person’s wishes cannot be given effect to at all—the interests of the protected person must be promoted;
d. the protected person’s life (including the person’s lifestyle) must be interfered with to the smallest extent necessary;
e. the protected person must be encouraged to look after himself or herself as far as possible;
f. the protected person must be encouraged to live in the general community, and take part in community activities, as far as possible.

There is a limited obligation to consult with the carers of the ‘protected person’ before making a decision (s 4(3)). If the guardian considers that such consultation would, in their opinion, ‘adversely affect the protected person’s interests’, they ‘must not consult’ with any carers (s 4(4)).

Amendments in 2001 placed the Guardianship Act squarely in the ‘best interests’ paradigm of substitute decision making. This is apparent in the definition of ‘the protected person’s interests’ (s 5A), which does not include any reference to the wishes of the person. The protected person’s interests are defined to include:

a. protection of the person from physical or mental harm;
b. prevention of the physical or mental deterioration of the person;
c. the ability of the person to
   (i) look after himself or herself; and
   (ii) live in the general community; and
   (iii) take part in community activities; and
   (iv) maintain the person’s preferred lifestyle (other than any part of the person’s preferred lifestyle that is harmful to the person);
d. promotion of the person’s financial security;
e. prevention of the wasting of the person’s financial resources or the person becoming destitute.
A guardian has powers under s 7(3):

a. to decide where, and with whom, the person is to live;
b. to decide what education or training the person is to receive;
c. to decide whether the person is to be allowed to work;
d. if the person is to be allowed to work—to decide the nature of the work, the place of employment and the employer;
e. to give, for the person, a consent required for a medical procedure or other treatment (other than a prescribed medical procedure);
f. to bring or continue legal proceedings for or in the name of the person.

A guardian's powers are limited (s 7B), and do not include the power to discipline the person or to do any of the following things for the person:

a. vote in an election;
b. make a will or other testamentary instrument;
c. consent to the adoption of a child;
d. give a consent to a marriage or civil union;
e. give a consent required for a prescribed medical procedure for the person.

For purposes of s 7B(e) – limited power for medical consent – a ‘prescribed medical procedure’ is defined in the Act’s Dictionary as:

a. an abortion; or
b. reproductive sterilisation; or
c. a hysterectomy; or
d. a medical procedure concerned with contraception; or
e. removal of non-regenerative tissue for transplantation to the body of another living person; or
f. electroconvulsive therapy or psychiatric surgery; or
g. any other medical or surgical procedure prescribed for this definition.

The limitation on a guardian’s giving consent for a prescribed medical procedure is addressed by a provision that enables the ACAT to give consent (s 70). In giving consent, the ACAT must have regard to the person’s ‘best interests’, taking into account:

a. the wishes of the person, so far as they can be ascertained; and
b. what would happen if it were not carried out; and
c. what alternative treatments are available; and
d. whether it can be postponed because better treatments may become available; and
e. for a transplantation of tissue—the relationship between the two people.

It is notable that ‘the wishes of the person, so far as they can be ascertained’, in s 70, differs from the definition of a person’s interests for purposes generally of decision making under the Act (s 5A).

3.1.3 Origins and history of the Guardianship Act

The ACT Legislative Assembly originally enacted the Guardianship Act during the ACT’s inaugural period of self-government. At the time of its enactment, the then Attorney-General, Terry Connolly MLA, recognised the need for modernisation of the laws surrounding the issue of legal capacity for people who may have impairment in their...
decision making abilities because of ‘intellectual, physical, mental or psychological incapacity’. The Guardianship Act was established for a person who

> needed assistance or protection from abuse, exploitation or neglect;
> was legally incompetent; or
> was unable to enter into particular transactions.

The Act contained a rebuttable presumption of legal competence for all people with disabilities.

Prior to self-government, individuals in the ACT who exhibited impairment in their decision making ability could become the subject of various orders issued by the ACT Supreme Court under the Lunacy Act 1898 (NSW). Before the Guardianship Act, legislation relating to issues of disability relied on language and principles that, according to John Bennett, had existed since the Middle Ages; the Australian Law Reform Commission considered this language to be ‘associated with negative connotations or used pejoratively’, and that it could be seen as lowering the dignity of people with disabilities.

The Guardianship Act established the Guardianship and Management Tribunal (‘the Tribunal’) to be administered by the Magistrates Court, but in a special jurisdiction where it was not part of that Court. The Tribunal was required to hold an inquiry before making any orders; it was able to hold its hearing wherever was appropriate and to conduct the inquiry informally and in a public way, ‘with as little regard to legal technicalities as is just’. The Tribunal was given inquisitorial powers, and was bound by the rules of natural justice. It was given the authority to appoint a guardian for a person determined by the Tribunal to be unable to make reasonable judgments relating to their health and welfare because of a physical, mental, psychological or intellectual condition, as a result putting their health or welfare substantially at risk. A manager was to be appointed if a person was legally incompetent because of a physical, mental, psychological or intellectual condition, and the question of competence could arise either if the person sought to enter a transaction relating to their property, or ‘it [wa]s in the person’s interests to preserve the person’s property by preventing a purported disposition of the property’.

The Guardianship Act also established a set of principles that would guide the Tribunal and guardians/managers, so that the orders would not be ‘overly intrusive’, and they were subject to review at least every three years. The powers given to guardians and managers were clearly limited to what was necessary in the circumstances, for example, under section 11 (which remains under the current Act):

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7 Connelly T. Explanatory Memorandum, Guardianship and Management of Property Bill 1991 (ACT), 1991, Legislative Assembly for the Australian Capital Territory (Original Explanatory Memorandum) at page 1; see also ACT Legislative Assembly, Hansard, 12 September 11991, pages 3216-3219, where Mr Connelly notes (page 3217) the 1989 Report of the Australian Reform Commission on the guardianship and management of property of persons in the ACT who are incapable of looking after their own interests.

8 Guardianship and Management of Property Act 1991 (as passed - No. 62 of 1991) (Guardianship Act as originally enacted): section 3(1).

9 Guardianship Act as originally enacted - see note 7: section 3(3). Section 3(3) of the 1991 Act said: The Tribunal shall apply the principle that, unless the contrary is proved, persons suffering from physical, mental, psychological or intellectual conditions are legally competent and their decisions are reasonable’.

10 Lunacy Act 1898 (NSW).

11 Bennett J. A History of the Supreme Court of New South Wales (Law Book Co. 1974), at page 125, quoted in the ALRC report, paragraph 2.21.


13 Original Explanatory Memorandum – see note 6: paragraph 2, page 1.

14 Guardianship Act as originally enacted - see note 7: Section 33.

15 Guardianship Act as originally enacted - see note 7: Section 34. In the Original Explanatory Memorandum (see note 6), it was stated that this allowed the Tribunal to sit at a location and at a time that may suit the special needs of a represented person': page 8.

16 Guardianship Act as originally enacted - see note 7: section 37(2).

17 Guardianship Act as originally enacted - see note 7: sections 37(3)-41.

18 Original Explanatory Memorandum – see note 6: Clause 7, page 3, and section 7 in the Guardianship Act as originally enacted - see note 7.

19 Guardianship Act as originally enacted - see note 7: section 8, especially sub-section 8(1)(b).

20 Guardianship Act as originally enacted - see note 7: section 19.
The powers conferred on a person’s guardian or on a manager of a person’s property are to be no more restrictive of the person’s freedom of decision and action than is necessary to achieve the purpose of the order.

When introducing the Guardianship Act, the Attorney-General stated that it was to provide ‘a simple and informal system’ of guardianship and management of people and their property, where the person was unable to make decisions because of various forms of incapacity. Guardianship was, where possible, to rest in a natural person who was relative or close friend of the protected person, although a manager could be the guardian, or the Public Trustee or another trustee company could be appointed jointly with the guardian. In the absence of a suitable person to act as guardian, a community advocate could be appointed as a last resort.

3.1.4 The 2001 amendments: reversion to paternalism

There have been significant amendments to the legislation since its commencement. Some have altered the language used and the principles under which decision-makers operate; others have added new and significant provisions relating to medical consent.

Both the principles and the language of the original 1991 Guardianship Act were more consistent with the paradigm espoused by UN Convention and the ALRC Final Report than were the subsequent amending provisions. In contrast, these amendments expanded the power to grant guardianship or management over someone’s decision making, thus spreading the net of substitute decision making.

The effect of the 2001 amendments was to establish a more paternalistic, less rights-based approach to guardianship and decision making than seems was the intention of the Act in its original form. This is illustrated by an amendment that changed reference in the legislation from ‘represented person’ to ‘protected person’.

In its original terms, the Act set out as decision making principles that the person’s views and wishes, so far as they could be ascertained, should receive paramount consideration, and that decisions made by the substitute decision-maker ‘should be, as nearly as possible, the decisions that he or she would have made if not affected by the condition concerned’. In the Guardianship Act as originally enacted, there was a subsidiary requirement that the person’s welfare and interests be appropriately protected, but the paramount consideration could be seen as a form of representative ‘will and preferences’. This compares to the new set of principles in the 2001 Amending Act, which are squarely embedded in the ‘best interests’ paradigm. The Explanatory Memorandum for the amendments criticised the original provisions as creating ‘conflict between the person’s wishes and their welfare’, and stated that ‘[g]iving effect to the former may endanger an individual’s personal and financial welfare’. Circumstances in which a manager could be appointed were expanded, and ‘risk to property’ became a new basis for seeking guardianship.

The obligations of guardians and managers also changed. Under its original terms, the Guardianship Act set out, in section 14, obligations which characterised the arrangements as a ‘representative’ form of decision making: the guardian or manager was ‘to act, so far is proper, as the person would have acted in the circumstances if he or she were not affected by the condition concerned’. Only in a particular case, where it was not possible to determine how the person would have acted, was the guardian or manager allowed to substitute a ‘best interests’ based decision, subject to further considerations.

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21 Original Explanatory Memorandum – see note 6: paragraph 1, page 1.
22 Original Explanatory Memorandum – see note 6: Clause 9, page 4.
24 Guardianship Act as originally enacted - see note 7: sub-sections 3(2)(a) and 3(2)(b) in particular, but see sub-section (2) more generally as well.
25 Guardianship Act as originally enacted - see note 7: sub-section 3(2)(c).
29 2001 Amending Act – see note 22, section 7 (1) (b)(ii).
30 Guardianship Act as originally enacted - see note 7: sub-section 14(1).
31 Guardianship Act as originally enacted - see note 7: sub-section 14(3).
32 ACT Law Reform Advisory Council
In 2001, the principles were amended to refer to a person’s interests, which was a defined term. What had been, for example, a principle that a person’s ‘views and wishes, so far as they can be ascertained, should be respected’, was amended to read that a person’s ‘wishes, as far as they can be worked out, must be given effect to, unless making the decision in accordance with the wishes is likely to significantly adversely affect the protected person’s interest (emphasis added). The amendments clearly embedded an approach of substitute decision making in a person’s ‘best interests’.

3.1.5 The 2008 amendments: Health Attorney

In 2008, a new Part 2A of the Guardianship Act was introduced to create a new role, the Health Attorney. When a person cannot give consent in a medical emergency, the common law permits a medical or dental practitioner to act without consent if they honestly believe on reasonable grounds that the treatment is necessary to avert a serious and imminent threat to the patient’s life or physical or mental health. The common law doctrine of emergency acts as a defence for the doctor against a claim of battery. The common practice was, when possible, to ask the person’s relative or friend for consent, but this was not required by legislation in the ACT. Part 2A was introduced to establish a statutory framework for consent in a medical emergency, and to bring the ACT into line with other jurisdictions, such as NSW, where a close relative or friend can consent to treatment on behalf of someone with impaired decision making ability. According to the Explanatory Statement,

[the scheme is also consistent with the general expectation in the community that where a person lacks capacity, a person close to him or her would be involved in decisions relating to provision of their medical care.]

Part 2A applies when a person has impaired decision making ability in relation to giving consent, requires medical treatment, has not made arrangements for an enduring power of attorney, and does not have a guardian. In those circumstances, a medical or dental practitioner must determine who ‘is best able to represent the views of the protected person’ to be the person’s health attorney. To make this determination, the practitioner must follow the priority order set out in s 32B: first, the continuing domestic partner, then a carer, and then a close relative or friend.

When a health professional seeks the health attorney’s consent on behalf of the person with impaired decision making ability, the health professional must give the health attorney extensive prescribed information to assist the attorney in making a decision on behalf of the impaired person (s 32G). Under section 32E, the actions of the health attorney and the health professional are bound by the decision making principles set out in section 4(2). The consent of the health attorney is effective for six months before the treating doctor needs to notify the public trustee and guardian that the treatment is still ongoing (s 32J).

If the health attorney refuses consent or there is dispute between the people who could be health attorneys for the protected person, then the health professional must refer the matter to the public trustee and guardian (s 32H). If the public trustee and guardian cannot help the parties to reach agreement then the matter must be referred to ACAT (s 32I).

The 2008 amendments created some complexities and confusion. In particular, Part 2A uses the same term, ‘protected person’, as is used the rest of the Act, but defines it differently (s 32A). The definition for Part 2A excludes people who are under guardianship (that is, people who are ‘protected people’ under the other parts of the Act) and people who have an attorney with authority to give consent for medical treatment under an enduring power of attorney.

In addition, the provisions setting up the nature of the health attorney role in section 32D create the health attorney as a representative decision-maker. This was emphasised in the Explanatory Statement, which states that potential

32 Guardianship Act s 5A, introduced by the 2001 Amending Act – see note 22.
35 This matter was noted by Mr Corbell in his speech on the presentation of the Bill on 7 August 2008: see ACT Legislative Assembly. Hansard. 7 August 2008: at page 3009.
38 2008 Amending Act – see note 32: sections 32D and 32F
health attorneys ‘are likely to be those best placed to understand, the wishes, views and feelings of the protected person’. However, section 32E imposes an additional – and what appears to be contradictory – ‘best interests’ obligation on both the health professional and the health attorney, by requiring them to follow the decision making principles in section 4(2). These create a substitute ‘best interests’ decision making role.

In combination, these requirements create a potential conflict when, for example, the health attorney’s view of the person’s ‘best interests’ are at odds with their understanding of the wishes, views and feelings of the protected person. The consequence is that the law in relation to a substitute decision-maker refusing treatment for a person who is incompetent to make a decision themselves is far from certain.

3.1.6 The Guardianship Act and powers of compulsion

The potential powers of a guardian to make decisions in the life of a protected person can be extensive under the current legislation. While there are some limitations about what medical procedures can be approved by a guardian under section 7B(e) of the Guardianship Act, consent for most normal medical treatment for both physical and mental health is now able to be approved by the guardian. Recent consequential amendments, accompanying the Mental Health Act 2015, removed general mental health treatment from the list of ‘prescribed medical procedures’, now leaving only electroconvulsive therapy and psychiatric surgery in the definition, and therefore, as exclusions from the guardian’s power to decide. Similarly, a guardian may determine where and with whom a protected person lives. In both situations, under the current Guardianship Act, the guardian may decide these actions against the wishes of the person, if the guardian forms the view that carrying out the person’s wishes would be against the person’s interests. The extent of any compelling force permissible to enact these decisions and in what circumstances such force may be used is not clear. The lack of procedural safeguards was raised as a concern in submissions, particularly compared with the safeguards now provided in the Mental Health Act 2015. The use of force to impose a decision for mental health treatment compels the medical team to seek an involuntary treatment order through ACAT, even where the person has given advance consent.

3.2 Other ACT laws that recognise substitute decision making

Other ACT legislation which create substitute decision making mechanisms include the Powers of Attorney Act, the Health Directions Act and the Mental Health Act. The relevant provisions of these Acts are summarised below.

3.2.1 Powers of Attorney Act

A general power of attorney operates only when the principal has decision making capacity (s 7), while an enduring power of attorney operates as a general power of attorney while the principal has decision making capacity and continues to operate after the principal becomes a person with impaired decision making capacity (s 8). An enduring power of attorney cannot be revoked once the principal has impaired decision making capacity.

A person has decision making capacity when they can ‘make decisions in relation to their affairs and understand the nature and effect of these decisions’ (s 9(1)). Correspondingly, someone has impaired decision making capacity if they cannot make such decisions or do not understand their nature and effect (s 9(2)). A person does not have impaired decision making capacity only because they are eccentric, make unwise decisions, express a particular political or religious opinion, have a particular sexual orientation or express a particular sexual preference, engage or have engaged in illegal or immoral conduct, take or have taken drugs including alcohol (s 91). A question about
whether a person had decision making capacity at a particular time can be resolved by a certificate from a doctor (s 87).

An attorney does not have power to make decisions on ‘special personal matters’, including making or revoking a will or power of attorney; voting; consenting to the adoption of a minor child of the principal; and consenting to marriage (s 36). An attorney does not have power to make decisions on ‘special health matters’ including live tissue donation, sterilisation or termination of pregnancy unless necessary to treat organic malfunction or disease; participation by the principal in medical research or experimental health care; electroconvulsive therapy or psychiatric surgery; or other prescribed health care (s 37). General treatment for mental illness was removed from the list of special health matters, with the commencement of the recent Mental Health Act.

Concerns were raised in submissions to and consultations with the Council that there were inadequate safeguards for older people in relation to the operation of an enduring power of attorney, and in relation to decision making more broadly, particularly in relation to health decisions and where there are disputes between family members who have substitute powers of decision making.43

**Enduring powers of attorney and supported decision making**

Under an enduring power of attorney, an attorney can ask for treatment to be withheld or withdrawn from a principal who has impaired decision making capacity. This can only occur after seeking medical advice, and if the attorney believes on reasonable grounds that the principal would make that decision, if the principal could make a rational judgment and were to give serious consideration to their own health and wellbeing (s 46). This is also subject to the principal’s right to relief from pain, suffering and discomfort and to the reasonable provision of food and water (s 87). Section 46, read in conjunction with section 87, attempts to give the attorney authority to give effect to what the principal’s will and preference would be. This is, however, at odds with s 85, which allows specific health professionals to approach the Public Advocate if the health professional believes that the attorney’s decision is not in the best interests of the principal. The concept of ‘best interests’ is not defined. The scope of the authority in s 46 seems, as well, at odds with the tenor of General Principle 1.11 noted below.

**General Principles relating to impaired decision making capacity**

The General Principles set out in Schedule 1 to the Powers of Attorney Act ‘must be complied with to the maximum extent possible by a person who exercises the functions of an attorney under an enduring power of attorney in relation to a principal with impaired decision making capacity’ (s 44). The Principles are quite different from the principles set out in both the current Guardianship Act and the Mental Health Act.

So far as decision making in concerned, Principle 1.6 seems more consistent with supported decision making:

1. An individual has a right to take part in decisions affecting the individual’s life to the greatest extent practicable.
2. Without limiting subsection (1), an individual also has a right to take part in decisions affecting the individual’s property and finance to the greatest extent practicable.
3. The right of the individual to make the individual’s own decisions must be preserved to the greatest extent practicable.
4. If an individual’s wishes or needs cannot be expressed by the individual, the person exercising power in relation to the individual must try to work out, as far as possible, from the individual’s past actions, what the individual’s wishes and needs would be if the individual could express them and take those wishes and needs into account.
5. However, a person exercising a function in relation to an individual must do so in a way consistent with the individual’s proper care and protection.
6. An individual’s views and wishes may be expressed orally, in writing or in another way, including, for example, by conduct.

43 See, for example Submission 14, Council on The Ageing ACT; Submission 15, Leading Aged Services.
Provided with Principle 1.6(3) are examples of how an individual’s right to make their own decisions can be preserved:

> The individual must be given any necessary support, and access to any necessary information, to allow the individual to take part in decisions affecting the individual’s life to the greatest extent practicable.

> To the greatest extent practicable, the individual’s views and wishes must be sought and taken into account before exercising power in relation to the individual.

> Power in relation to the individual must be exercised in the way that is least restrictive of the individual’s rights.

By contrast, Principles 1.6(4) and (5) revert to the tenor of substitute decision making, requiring an attorney only to ‘take into account’ what the individual’s wishes and needs would be, in a way ‘consistent with the individual’s proper care and protection’, but without any explicit regard to the individual’s rights.

Principle 1.11 also departs from the supported decision making approach suggested by Principle 1.6. Principle 1.11 states:

1. An individual is entitled to have decisions about health care matters made by an attorney—
   a. in the way least restrictive of the individual’s rights and freedom of action; and
   b. only if the exercise of power—
      (i) is, in the attorney’s opinion, necessary and appropriate to maintain or promote the individual’s health and wellbeing; or
      (ii) is, in all the circumstances, in the individual’s best interests.

2. An individual’s wishes in relation to health care matters, and any information provided by the individual’s health care provider, must be taken into account when an attorney decides what is appropriate in the exercise of power for a health care matter.

This Principle is again at odds with the supported decision making approach suggested by in Principle 1.6 and, more problematically, with the terms of s 46. It is hard to see how a decision can both comply with s 46 and with Principle 1.11. This leaves an unresolved inconsistency between supported decision making (Principle 1.6 and s 46) and substitute decision making (Principles 1.6(4), 1.6(5) and 1.11).

### 3.2.2 Powers of Attorney Amendment Act 2016 – Medical Research Power of Attorney

The Council’s terms of reference necessarily include a review of the operation of the Powers of Attorney Act, as noted. Independently of the Council’s review, the Government introduced the Powers of Attorney Amendment Bill 2015 to the Legislative Assembly on 19 November 2015. The Act was passed on 18 February 2016 and notified on 1 March 2016, but not yet commenced at the date of this report. These changes are referred to here as ‘the medical research amendments’. The Act amends the decision making powers of substitute decision-makers in relation to medical research under several Acts that are the subject of the Council’s review. Its default commencement date is 1 September 2016.

This Act further complicates legislative provisions in the ACT in respect of decision making for people with impaired decision making ability, but confirms the Council in its view that a single approach must be taken.

The specific issue addressed by this Act is whether people with impaired decision making ability can participate in medical research. Prior to the medical research amendments, a substitute decision to consent to participate in medical research was not permissible under an enduring power of attorney. The power of a guardian or health attorney to make a substitute decision to consent to participate in medical research was, by comparison, unclear and turned on whether participation in medical research could be characterised as ‘treatment’.

The explanatory memorandum for the Powers of Attorney Amendment Bill 2015 stated that:

> the policy objective of the amendments is to remove barriers to people with impaired decision making capacity participating in medical research. Removing these barriers may allow these people to receive beneficial treatment not otherwise available to them and will assist health researchers to develop innovative treatments which may benefit a class of people with a certain condition. The amendments
are also aimed at making the process for deciding about a person’s participation in medical research consistent for all substitute decision-makers.\(^{44}\)

The Attorney-General said that the approach put forward ‘strikes an appropriate balance between removing barriers to participation in medical research and protecting a person’s right not to be involved in medical research’.\(^{46}\)

The medical research amendments create a medical research power of attorney in the enduring power of attorney provisions of the Powers of Attorney Act. The Act also amends the Guardianship Act in relation to both guardianship and health attorney provisions, and the Health Directions Act, to allow greater participation of people with impaired decision making ability in medical research.

The definition of medical research is two-tiered: ‘low-risk research’ and ‘medical research’.\(^{46}\) ‘Low-risk research’ is research carried out for medical or health purposes, apart from a clinical trial, that poses no foreseeable risk of harm to the person, other than any harm usually associated with the person’s condition, and does not change the treatment appropriate for the person’s condition. A health attorney can only consent to participation in ‘low-risk research’.

‘Medical research’ is research in relation to the diagnosis, maintenance or treatment of a medical condition that the person has or has had or to which the person has a significant risk of being exposed, including experimental health care and clinical trials. ‘Experimental health care’ is research into health care that need not be medical in nature, is delivered as part of a test or trial, and has not yet gained the support of a substantial number of practitioners in that field of health care.

The research must be approved by a human research ethics committee constituted in accordance with and acting in compliance with the National Health and Medical Research Council (NHMRC) National Statement on Ethical Conduct in Human Research. (see s 41A and 41D(2)(a)).

Under the medical research amendments, only an attorney or guardian can consent to participation in medical research. They must be satisfied that – and an independent doctor must assess whether – the person with impaired decision making ability will not recover their ability to consent before their participation in the research concludes. Under section 41D(2)(c) the attorney or guardian must also be satisfied on reasonable grounds that

- the research relates to the diagnosis, maintenance or treatment of a condition that the principal has or has had, or is at significant risk of:
- the research may benefit the principal or others with the condition,
- the potential benefit outweighs any potential risk or inconvenience to the principal or any potential adverse impact on the principal’s quality of life, and
- participation in the research will not unduly interfere with the principal’s privacy.

The medical research amendments to the Powers of Attorney Act do not modify the General Principles that ‘must be complied with to the maximum extent possible by a person who exercises the functions of an attorney under an enduring power of attorney in relation to a principal with impaired decision making capacity’ (s 44 of the Powers of Attorney Act). However, under section 41B, the medical research amendments require a medical research power of attorney to abide by the same decision making principles as are in the Guardianship Act. The confusion within the Power of Attorney Act Principles in the Schedule to that Act have been discussed above and these are in the Council’s view magnified in the operation of the new medical research attorney provisions. In addition, the Council has concluded that the decision making principles in the Guardianship Act are not compliant with the UN Convention and are inconsistent with the representative nature of the health attorney provisions.

The new schema goes further than simply providing a consistent arrangement for substitute health care decision-makers in relation to medical research. For example, it modifies the precedence given to health directions made under the Health Directions Act, discussed below so far as participation in medical research is concerned. It also gives retrospective power for an attorney to provide research participation consent for a principal, where an attorney


\(^{46}\) Section 13 of the Act sets out a new Part 4.3A to the Power of Attorney Act. This includes a new Definition section (s 41A) that defines these terms. Consequential amendments are also made to the Guardianship Act and the Health Directions Act in Schedule 1, which brings these definitions into these Acts as well.
was given power over health care matters in an enduring power of attorney made prior to the medical research amendments (s 41A ‘medical research power of attorney’ definition).

The medical research amendments also limit the right of free consent to participation in medical or scientific experimentation and treatment under section 10(2) Human Rights Act by allowing a guardian or attorney to make a substitute decision giving consent. The ACT Attorney has argued that the limitation is justified because of the benefits that flow from the person participating in such research. 47

The medical research amendments do not utilise supported decision making, but continue a ‘best interests’ substitute decision making regime, which the Council submits is inappropriate and inconsistent with the UN Convention.

3.2.3 Mental Health Act 2015

Principles and Objectives

The new ACT mental health legislation includes a number of provisions which bring the legislation more into line with the UN Convention, the Human Rights Act and other international rights instruments. 48 For instance, the objects of the Mental Health Act (contained in s 5) include provisions that are consistent with the UN Convention Preamble, Purpose (Article 1) and General Principles (Article 3), including to:

b. promote the capacity of people with a mental disorder or mental illness to determine, and participate in, their assessment and treatment, care or support, taking into account their rights in relation to mental health under territory law; and

... 

d. facilitate access by people with a mental disorder or mental illness to services provided in a way that recognises and respects their rights, inherent dignity and needs.

The Principles under section 6 of the Mental Health Act also reflect many of the directions in the UN Convention. For example, when exercising a function under the Act, the following principles must be taken into account:

e. a person with a mental disorder or mental illness has the same rights and responsibilities as other members of the community and is to be supported to exercise those rights and responsibilities without discrimination;

f. a person with a mental disorder or mental illness has the right to—

(i) consent to, refuse or stop treatment, care or support; and

(ii) be told about the consequences of consenting to, refusing or stopping treatment, care or support;

g. a person with a mental disorder or mental illness has the right to determine the person's own recovery;

h. a person with a mental disorder or mental illness has the right to have the person’s will and preferences, to the extent that they are known or able to be known, taken into account in decisions made about treatment, care or support;

i. a person with a mental disorder or mental illness has the right to be given timely information, in a way that the person is most likely to understand, to allow the person to make decisions or maximise the person’s contribution to decision making about the person's assessment and treatment, care or support;

j. a person with a mental disorder or mental illness has the right to be assumed to have decision making capacity, unless it is established that the person does not have decision making capacity;

k. services provided to a person with a mental disorder or mental illness should—

(i) respect the informed consent of the person to the person’s assessment and treatment, care or support including consent as expressed in an advance consent direction; and

(ii) support and allow the person to make the person’s own decisions; and

47 Health Research Explanatory Statement 2015 – see note 44: pages 3-6, which sets out the Government’s views about the compliance of the legislation with the Human Rights Act 2004 (ACT).

48 These are detailed in full in the Mental Health Bill 2015 Explanatory Statement delivered in the ACT Legislative Assembly by the Minister for Health Simon Corbell on 4 June 2015 (Mental Health Act Explanatory Statement): paragraph 2.8-2.27, pages 2-7.
(iii) be provided in a way that considers and respects the preferences of the person, including those expressed in an advance agreement; and

(iv) promote a person’s capacity to determine the person’s recovery from mental disorder or mental illness; and …

(viii) be provided in a way that ensures that the person is aware of the person’s rights

The Explanatory Statement for the Bill centred the aim of the Bill on ‘the right to the highest attainable standard of mental health’ and detailed extensively how the Bill is compatible with the Human Rights Act.

Decision making under the Mental Health Act

Perhaps most significantly, for the purposes of this Report, the new Mental Health Act has specific principles relating to decision making. Decision making is defined in the Act (s 7) as follows:

… a person has capacity to make a decision in relation to the person’s treatment, care or support for a mental disorder or mental illness (decision making capacity) if the person can, with assistance if needed—

a. understand when a decision about treatment, care or support for the person needs to be made; and

b. understand the facts that relate to the decision; and

c. understand the main choices available to the person in relation to the decision; and

d. weigh up the consequences of the main choices; and

e. understand how the consequences affect the person; and

f. on the basis of paragraphs (a) to (e), make the decision; and

g. communicate the decision in whatever way the person can.

The Principles that must be taken into account when considering a person’s decision making capacity under the Act, as set out in section 8 below, are a ‘blended’ form. The principles have moved towards supported decision making and the recognition that decision making ability varies at different times and across different decisions. However, when someone has no decision making capacity at a particular point, under section 8(3), the requirement for substitute decision making becomes a ‘best interests’ test. Section 8 provides:

1. In considering a person’s decision making capacity under this Act, the following principles must be taken into account:

a. a person’s decision making capacity is particular to the decision that the person is to make;

b. a person must be assumed to have decision making capacity, unless it is established that the person does not have decision making capacity;

c. a person who does not have decision making capacity must always be supported to make decisions about the person’s treatment, care or support to the best of the person’s ability;

d. a person must not be treated as not having decision making capacity unless all practicable steps to assist the person to make decisions have been taken;

e. a person must not be treated as not having decision making capacity only because—

(i) the person makes an unwise decision; or

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(ii) the person has impaired decision making capacity under another Act, or in relation to another decision;

f. a person must not be treated as having decision making capacity to consent to the provision of treatment, care or support only because the person complies with the provision of the treatment, care or support;

g. a person who moves between having and not having decision making capacity must, if reasonably practicable, be given the opportunity to consider matters requiring a decision at a time when the person has decision making capacity.

2. A person’s decision making capacity must always be taken into account in deciding treatment, care or support, unless this Act expressly provides otherwise.

3. An act done, or decision made, under this Act for a person who does not have decision making capacity must be done in the person’s best interests.

4. In considering a person’s decision making capacity under this Act, any approved code of practice under section 198 must be taken into account.

Section 198 allows the chief psychiatrist to approve a code of practice to provide guidance on assessing whether a person has decision making capacity. This code is a notifiable instrument.

Expressing will and preferences and substitute decision making

The Mental Health Act enables a person with an existing or latent mental disorder or mental illness to make provision, at a time when they have decision making capacity, in anticipation of when they may lack that capacity in future, including (in summary) provisions for:

- nominating someone to be the person’s ‘nominated person’ (Part 3.2) – the nominated person’s main function is to help the person with a mental disorder or mental illness by ensuring that that person’s interests are respected if the person requires treatment, care or support for a mental disorder or mental illness; they also have a right to receive information, to be consulted about decisions in relation to the treatment, care or support of the person who nominated them and to undertake other functions given by the Act. This does not provide a substitute decision making power;

- making an advance agreement (s 26) which sets out for the person’s treating team information the person considers relevant to their treatment, care or support and any preferences the person has for practical help they may need as a result of their mental disorder or mental illness – this agreement is placed on someone’s medical record and provides information about the person’s wishes and preferences, to guide treating mental health professionals and substitute decision makers (as set out below);

- making an advance consent direction (s 27), which allows a person to make a direction about a range of matters to which they consent or refuse consent, in the event of them not having “decision-making capacity” – these directions can cover treatment; care or support; medications or procedures, as well as directions about who may and may not be provided with information about the person’s treatment, care or support.

To be valid, any such direction must have involved discussion with the treating team about possible options at a time when the person had decision making capacity. The administrative requirements for different treatment provisions vary. For example, advance consent directions for electroconvulsive therapy and psychiatric surgery require a higher level of documentation and witnessing than other decisions.

So far as application of these agreements or consent directions are concerned, a mental health professional must, before giving treatment, care or support to a person with a mental disorder or mental illness who lacks decision making capacity, take reasonable steps to find out whether an advance agreement or advance consent direction is in force. If there is, then the mental health professional treating the person is bound by their instructions in that agreement or direction so far as practicable (s 28). If the person has impaired decision making capacity and they resist the treatment that they have consented to under the advance consent direction, the Act is also clear that the treatment may not be given. Section 28(3)(d) states that the health professionals must not apprehend, detain, restrain or use force to give effect to the direction. In that case, an order must be sought from ACAT. Section 28(4) provides:

- If an advance consent direction is in force in relation to a person but the person resists being given treatment, care or support to which they have consented under the direction, a mental health professional may give the treatment, care or support to the person only if the ACAT, on application by the mental health professional, orders that the treatment, care or support may be given.
The Mental Health Act sets out new arrangements between other substitute decision makers and the person so far as mental health treatment is concerned. Until 1 March 2016, under the Power of Attorney Act, ‘treatment for mental illness’ was a special health care matter under section 37(e). Because of this, an attorney appointed by someone to make health care decisions was not able to make decisions related to mental health, and consent needed to be obtained through ACAT under the Mental Health (Treatment and Care) Act 1994. There was a similar exclusion under the ‘prescribed medical procedures’ definition of the Guardianship Act. These exclusions for the ‘treatment of mental illness’ were removed in the amending legislation, and became operational at the same time as the new Mental Health Act. This means that substitute decision-makers can now make decisions in relation to treatments for mental illness, if they have power to make other health decisions. So far as advance agreements and advance consent directions are concerned, if the person has a guardian or an attorney, the consent of the guardian or attorney is not required if consent is provided by the person in an advance agreement or advance consent direction (ss 30(3) and 31(4) respectively). The decision making functions of a guardian or an enduring attorney must ‘be exercised taking into account the advance agreement or advance consent direction’ (ss 30(2) and 31(3)). In the case of an attorney, under section 31(2), they are required to use the wishes expressed in these documents, when determining the person’s wishes or needs under the decision making principles in Schedule 1 of the Power of Attorney Act. Presumably, where these documents are silent on a specific treatment option that is not statutorily precluded, the general powers of these people to make a substitute decision continue.

After it is decided to give treatment, care or support to a person, there are strong duties to disclose information both to the person and to other associated people (such as nominated people, guardians or attorneys, health attorneys and others), advising of the various rights of the person under the Mental Health Act and more generally, including the right to a second opinion, to legal advice, to nominating someone, and to make an advance agreement or advance consent direction (s 15).

**Compulsory assessment and treatment orders**

ACAT retains an important judicial role in relation to mental health orders under the new legislation (s 37). A person with a mental illness or disorder may apply for an Assessment Order for themselves (s 33) if they believe themselves to be, because of mental disorder or mental illness, unable to make reasonable judgments about matters relating to their own health or safety, unable to do something necessary for their own health or safety, or likely to do serious harm to others. An application can also be made by someone else on these same grounds (s 34) or by the police when the person is alleged to have committed an offence (s 35). Assessment orders allow someone with a mental illness or mental impairment to be assessed and, where necessary for this to occur, detained in a mental health facility during such an assessment (s 35).

ACAT has power to act against the consent of someone in relation to an emergency order for assessment when there is ‘a serious concern about the immediate safety of the person, the applicant for the order or another person arising out of the application process’ (s 39). ACAT must provide the chief psychiatrist with written notice of this serious concern (s 39(2)(a)) and notify the Public Advocate immediately after such order is made (s 41).

Before an involuntary treatment or other order is made, ACAT must undertake an assessment (s 56), and must take into account ‘the views and wishes of the person, so far as they can be found out, including in an advance agreement; and an advance consent direction’.

Under a psychiatric treatment order, the chief psychiatrist can impose a range of involuntary processes (s 65), including confinement, restraint, involuntary seclusion and forcible administration of medication, but only to the degree that is reasonable and necessary to prevent harm to the person or others, or to ensure the person remains in custody under the order.

When a person with a mental disorder is assessed under an assessment order, or is subject to an application for a mental health order or a forensic mental health order, ACAT may, instead, make a community care order (s 66). A community care order can be made when a person refuses to receive treatment, care or support and ACAT believes on reasonable grounds that, because of their mental disorder, the person is doing or is likely to do serious harm to...
themselves or someone else, or is suffering, or is likely to suffer, serious mental or physical deterioration, to an extent that outweighs the person’s right to refuse to consent. A community care order can require:

- that the person be given treatment, care, support, or medication,
- that they undertake a counselling, training, therapeutic or rehabilitation program,
- that their communication with other people be limited,
- that they live – or be detained – in an approved community care facility, and/or
- that they not approach a specified place or person or undertake stated activities.

If a person with a mental illness or mental disorder is under a mental health order, and they contravene it, there are powers under section 77 to give notice to the person to comply and, if they do not, then authority to police to apprehend the person and take them to the relevant approved facility. If the person absconds from the approved facility, there are powers under section 78 to authorise police to return them there. In both cases, ACAT and the Public Advocate must be notified of these actions in writing within 12 hours.

Emergency detention is permitted under Chapter 6 of the Act. A police officer or authorised ambulance paramedic may apprehend a person and take the person to an approved mental health facility if they believe on reasonable grounds that the person has a mental disorder or mental illness, and has attempted or is likely to attempt suicide or to inflict serious harm on themselves or another person (s 80(1)). Similarly, a doctor or mental health officer may apprehend a person and take the person to an approved mental health facility if they believe on reasonable grounds that the person who has a mental disorder or mental illness that requires immediate treatment, care or support in a restrictive environment, or their condition is likely to deteriorate within 3 days to such an extent as to require such treatment, care or support. In addition, the person must have refused to receive that treatment, care or support and the detention must be necessary for the person’s health or safety, social or financial wellbeing or for the protection of someone else or the public (s 80(2)). ACAT must, on application, review the above decision of a doctor or mental health officer within two working days after the day the application is made (s 80(3)).

Policy implications

The new Mental Health Act seeks to embody many of the principles and aims of the UN Convention. In particular, it focuses on involving patients as much as possible in decision making, and provides a will and preference model in relation to advance consent directions and advance agreements. Where these wishes are recorded in documents, but the person’s mental illness means they fight against their previously expressed will and preferences, the direction and agreement provides a useful starting point for ACAT. These documents help ACAT in considering whether making a compulsory treatment order is, first of all, consistent with the person’s will and preferences, as expressed before their decision making capacity was impaired. Once the matter becomes one for a compulsory mental health order, ACAT becomes the forum to review all the evidence before making the order (s 56).

However, the new legislation includes provisions which can both increase and decrease compliance, because of their links to substitute decision making mechanisms which use a “best interests” framework, and its own acceptance of this as the basis for decisions when someone is believed to have no decision making capacity because of their mental illness. For example, the introduction of mental health decision making powers to an enduring power of attorney to make substitute decisions could be argued to improve the possibility of someone chosen by the person being able to ensure their wishes are honoured. Where there is both an enduring power of attorney and an advance consent direction or advance agreement, this may well be the practical outcome. However, if the person does not have an advance consent direction or advance agreement, then the decision making principles come under different legislation, with different principles of decision making.

In addition, because the legislation provides for compulsory treatment and community care orders, which can be enforced against the person’s will and preferences, its consistency with the UN Convention can be debated. If, however, one looks at these situations in terms of other rights, like the right to life, the right to health and wellbeing and to access to services to meet needs, it may be that these provisions could be framed as consistent. The issues of compulsory treatment, restraint and seclusion raise complex questions in a range of other settings, where the Mental Health Act protections may not apply. This is discussed later in Part 10 and Recommendation 16. The issue of forensic detention remains an area which needs to be explored outside this reference, in the context of the UN Convention and issues related to criminal responsibility. This is an area identified in Recommendation 15 for further work.

While the Mental Health Act provisions make progress towards the goal of the UN Convention, they further highlight the complexity of having multiple inconsistent pieces of legislation dealing with impaired decision making ability.
3.2.4 Medical Treatment (Health Directions) Act 2006

The Health Directions Act allows a person with decision making capacity to set down their wishes in relation to some specific health care decisions in a health direction, expressing their ‘will and preferences’ and thereby constraining some substitute decision making.

A health direction cannot be made by a person ‘for whom a guardian is appointed’ or ‘who has impaired decision making capacity’ (s 7). Issues of substitute decision making arise in two circumstances. The first is if a person who makes a health direction later loses their decision making capacity and a guardian is appointed; the guardian must exercise any power to consent to treatment in a manner consistent with the health direction (s 18), giving effect to the person’s express will and preferences. However, under s 68B of the Guardianship Act, on application by the guardian, the ACAT may revoke all or part of the health direction.

Issues of substitute decision making also arise when someone who makes a health direction later makes an enduring power of attorney that deals with health matters. In that case, the health direction is automatically revoked (s 19), and the person’s will and preferences as expressed in the health direction no longer operate.

A health direction forms part of the ACT Health Directorate suite of advance care planning tools (‘Respecting Patient Choices’), which also include an enduring power of attorney and a statement of choices. This kit is designed to help people think through treatment choices, often in the context of end of life choices. This has now been in place for two years, but the take-up rate of the initiative has been low. One reason for this may be the very time-specific and condition-specific nature of many health care choices for which it is difficult to pre-plan.

3.3 Conclusions in relation to existing ACT substitute decision making legislation

In summary:

> The Powers of Attorney Act enables a legally competent person to create an enduring power of attorney, which operates only when the person’s decision making capacity becomes impaired. The decision to appoint an attorney, and the choice of the attorney, is a discretionary one, which has meant that the regulatory regime is less formal, and less subject to regulatory oversight, than with guardianship, even though the roles of attorney and guardian can be quite similar in practice. Once the enduring powers of attorney becomes operative, the principal, whose decision making capacity has become impaired, is exposed to the same risks, but without the same safeguards as guardianship provides.

> The various provisions relating to substitute decision making in health legislation overlap and conflict with each other. This creates an administratively complex process for working out what and who has priority where someone’s decision making capacity becomes impaired. This is further complicated if the cause of the impaired decision making capacity relates to mental health, given the ‘nominated person’, and ‘advance agreements’ provisions and ‘advance consent directions’ apply only to people under the Mental Health Act.

> Different provisions take different approaches to the same end. Sometimes a ‘best interests test’ is used, eg when a guardian decides a health matter under the Guardianship Act; sometimes a representative ‘will and preferences’ approach is used, eg when a guardian is appointed after someone has executed a health direction, the guardian must exercise their power consistent with the health direction. At times, these approaches conflict, eg at the intersection between health attorneys and the Guardianship Act provisions.

> The new mental health legislation gives some effect to the supported decision making requirements of the UN Convention. However, these measures are available only to those to whom the Act applies, and are themselves qualified. For example, powers relating to involuntary treatment, use of restraint, and enforceable directions can be exercised in a person’s ‘best interests’ without consent, or with consent through substitute decision making.

It is apparent that these different legislative provisions take different approaches to what is essentially the same consideration: the making of decisions in circumstances where a person’s decision making capacity is impaired. It is the Council’s view that there would be significant community benefit in establishing a single coherent framework, informed by consistent underlying principles, for all occasions when a decision must be made by or for a person whose decision making ability is impaired.
PART 4: ESSENTIAL ASPECTS OF GUARDIANSHIP LAW

Overview of this Part

The law of guardianship in the ACT is based on the same common law principles as elsewhere in Australia. The idea of legal capacity – when it exists, when it is lost, and when it is limited or impaired – is central to guardianship. For adults, the issue of guardianship only arises if there is a question about a person's legal capacity.

The question of a person's legal capacity arises principally when the person has to make a decision. When a person is said to lack the capacity to make a decision, the law of guardianship allows substitute decision making, and the usual criterion for that substitute decision is the ‘best interests’ of the person for whom the decision is made.

This Part describes the concept of legal capacity, the standard approach to substitute decision making, and the related idea of ‘best interests’.

4.1 Legal capacity

The concept of guardianship arose from the feudal times as one of the obligations of the Lord and then, later, the King to protect those who were vulnerable. This became part of the role of the Lord Chancellor, who led the courts’ equitable jurisdiction and was sometimes described as “the keeper of the King’s conscience”. The courts of equity exercised a ‘protective jurisdiction’ that included powers in relation to the ‘persons and property’ of ‘infants, idiots, lunatics and married women’; the oldest of these ‘protective jurisdictions’ related to those people classified as mentally incompetent.

Over time, law provided these crown ‘protections’ to more people. Professor Terry Carney provides a useful summary of this history so far as it relates to the first three of these:

The ancient English common law institution of personal or property guardianship of individuals with diminished competence was once entirely the province of superior courts under prerogative powers of the Crown, and covering three vulnerable groups, namely children, the mentally ill and those with an intellectual disability. It was a state protective device governed by a best interest test and a paternalist philosophy, but financially accessible to very few.

The courts’ duty in their protective jurisdiction was to act in the best interests of the people who were judged as lacking legal capacity. The judges were substitute decision-makers acting under the best interest paradigm, much as courts and tribunals still do today.

When a person (usually of wealth) was born with an intellectual disability, the King became the trustee of that person’s property and person for their lifetime, and if someone became legally incompetent through development of

52 The statute which consolidated the pre-existing customary lordly prerogatives into the powers of the King was called De Praeogativa Regis, and was enacted in 1324 by 17 Edw 2. C.9. For more discussion of the history, see Doron I. From lunacy to incapacity and beyond – Guardianship of the elderly and the Ontario experience in defining ‘legal incompetence’. 1999. Health Law in Canada, May, volume 19(4), pages 95-114, especially at page 100.

53 See In re W.M.(a person alleged to be of unsound mind), 1901 New South Wales State Reports, volume 3, pages 552-570, at page 561.


55 The Canadian Supreme Court detailed the history of the parens patriae jurisdiction in England, Canada and the USA in the important judgement of E (Mrs) v Eve [1986] 2 SCR 388, beginning at pp 407 in the judgement of La Forest J, an appeal case where a mother sought unsuccessfully to have a non-therapeutic sterilisation performed on her intellectually disabled daughter.


a mental illness or other ‘misfortune’ then the King held the person’s property until they recovered. In both cases, the person became ‘infantilized’ before the law, ‘having no legal control or authority over their body or property’. The management of their life and property was undertaken by a ‘committee’ of their estate, which could be one or more people, often family members. Although this was seen at that time as a benevolent and paternalistic approach, at times property was usurped through such arrangements. A finding of legal incompetence was often of indefinite duration, permanently impeding the person’s exercise of their legal rights, and transferring their property to the crown at least for their life-time.

Capacity means it is ‘me’ creating my own life – substitute decision making means it is ‘you’ making my life.

Comment at a public debate on Supported decision making

The common law principles which derive from this historical context presume that every adult has legal capacity, in the full sense of having both legal standing and legal agency. Legal capacity underpins people’s power to make decisions for themselves, including day to day decisions about:

- where to live
- who to live with
- what education and training to do
- what work to undertake
- how to spend leisure time
- what day to day decisions to make about food, clothes and everyday things, and
- what to spend our money on.

It allows us to enter and enforce contracts, to exercise various civic and community rights like voting and marriage, and to take legal action to protect his or her rights, or to be able to perform actions which have legal effect.

Laws such as guardianship and mental health laws define circumstances when a person is considered to have impaired or no legal capacity, in the sense that they are seen to have impaired or no legal agency; this is sometimes referred to as ‘legal incompetence’. Laws for powers of attorney anticipate the possibility that legal capacity, in the sense of legal agency, will be lost or given up. If someone is found to ‘lack capacity’ or to be ‘legally incompetent’ they can be prevented from participating in many activities, and decisions about their life can be taken out of their hands. It has been said that a ‘determination of incompetence is in some cases a stronger degradation of the human being than is being declared a criminal’.

4.2 Substitute decision making

The making of decisions is central to a person’s exercise of legal agency. To fully understand a regime that is concerned with decision making, it is important to appreciate the nature of that decision making. A regime that substitutes one person’s decision for another assumes that the person making the substitute decision is making a ‘normal’, rational, considered and independent decision. In fact, people’s decisions are often not rational, considered and independent, and often arrived at with the support of and involvement of others.

59 A decision about a person’s legal competence was made by a jury of 12 men; see Doron I. From lunacy to incapacity and beyond – Guardianship of the elderly and the Ontario experience in defining ‘legal incompetence’. 1999. Health Law in Canada, May, volume 19(4), pages 95-114, especially at page 100


An appreciation of these unacknowledged features of ‘normal’ decision making provides an essential context for a discussion about supporting people with impaired decision making ability. By the time a person reaches adulthood they are often assumed to have the ability to make decisions based on knowing, for example:

- how to gather information about what they want to make a decision about;
- how to weigh up the information and work out what is the right decision for them;
- how to make the decision, including seeking advice and delaying decisions;
- how to enact the decision – doing what is necessary to make it happen.

Regardless of this people make decisions differently, depending on the importance attached to the decision and emotions that are felt at the time. Some people, for example, are cautious, mulling over choices and sometimes, not making a decision because it is too hard. Another person may be risk averse. Some people are systematic decision-makers who carefully weigh up all the evidence before deciding; others make decisions rapidly, with only partial information, because of time constraints or because the outcome is not important.

Whatever the approach to decision making, most decisions have strong emotional elements; people decide on the basis of their ‘will and preferences’, consistently with their values, within limits imposed by financial and other constraints, and often unconsciously influenced by other considerations.

How quick come the reasons for approving what we like.

*Jane Austen ‘Persuasion’*

Much of the influencing conduct used in society, like advertising, recognises the emotional overlay of rational decisions. An example of the effect of emotion on decisions is when the same mistake in choosing an option is made repeatedly because of the feelings that motivate the decision. People do not necessarily learn from their mistaken choices – as would be rational – they do not always know or understand the non-rational feelings that have led to the decision.

But decision making is still seen as the ‘rational’ act of an individual. There is now significant evidence that most people do not make many of their decisions ‘rationally’. A decision is made and then justified by developing rational reasons for it.

A person’s perception of available choices in decision making is also shaped by the values and examples they see and experience in the society in which they live. Judgements of what choices or decisions are wise, unwise, normal or abnormal are shaped by these experience and by personal values and preferences. Being able to evaluate and make choices creates a life that a person recognises as their own. Sometimes a decision works out well and sometimes not. In some instances a decision can be revisited because of more information, and maybe the consequences of an earlier decision can be redressed and maybe not. People enjoy the right, and run the risk, of making a decision that may or may not be a good one.

In liberal democracies there is an embedded, often unspoken, conception of decision making as an isolated action of an individual who ponders options alone and then makes a decision about what they have reasoned is in their ‘own good’. There are many forms of informal decision making arrangements and people often trust others to make decisions for them, through the granting of a specific power, or spontaneously, or by agreement, in families, at workplaces and in social groups. These allowances are not usually characterised as ‘substitute’ decision making, because there is consent given to the decision-maker and the decision can usually be debated, varied or over-ridden by the decision-maker. They are more in the nature of delegated decisions.

Such ‘supported’ decisions are commonplace whether people have impaired decision making ability or not. As social and relational beings, people make decisions with and for others, particularly family and friends. A Submission to the Council noted:

> [the idea of] supported decision making acknowledges the role of social support in decision making by all people and also acknowledges that few people make decisions in isolation. Collaboration and

relationship building to promote autonomy and self-advocacy are core values. In this way, supported decision making reflects how most people make and weigh the choices in their life.\textsuperscript{65}

Chen is going out to dinner with someone special and he asks his friend for advice about what he should wear.

Tasman wants to put up new curtains in her flat, so she asks her mother and her partner to come with her to help choose the colour.

Most people seek and give advice, even about quite trivial decisions, from a friend, a life partner, or someone who happens to be nearby; in fact, it can be seen as the wisest path because sometimes others see things differently, and their insights might not be affected by the same emotions. Different people may be consulted for different decisions; for decisions involving technical issues, for example, advice may be sought from a professional. In personal decisions decision-makers often preferentially select advice that supports their preferences.

There are common barriers to a person's making a decision, affecting the decision making process from information gathering and evaluation to making and enacting the decision. The barriers can include lack of information, not fully understanding the information that is available, not knowing or understanding the range of available choices or the implications of some choices. As well there are subjective barriers, such as a person's emotional state (eg relaxed, afraid, excited or depressed), their physical state (eg tired, hungry or in pain), and even the time of day or place where the decision is being made. Most people may have difficulty making a decision, for example, in a noisy and stressful place when they are tired and under time pressure, or when they feel threatened, or where they have previously had a bad experience.

There is a problematic culture surrounding the lives of people with disabilities. This includes a significant preoccupation with risk management and the pervasive attitudes that people with disabilities do not know their own interests, and therefore need protection from themselves and from society. Current guardianship practices are a product of this culture and major cultural change will be needed to address this.

\textit{Advocacy for Inclusion, Submission 6, page 16.}

4.3 ‘Best interests’

When a person is found to lack capacity to make their own decisions, the usual legal approach in the ACT and elsewhere has been for another person – sometimes called a guardian, financial manager or an attorney when formally appointed –to be as substitute decision-maker on behalf of the person said to ‘lack capacity’. For ease of discussion in the following paragraphs, a person involved in any of these roles in a formal way is called a ‘substitute decision-maker’, the person subject to substitute decision making is called the ‘person’, and the relationship is called ‘guardianship’.

Laws regarding legal capacity usually require the substitute decision-maker to make decisions in the ‘best interests’ of the person. This privileges the substitute decision-maker’s view of what is in the best interests of the person over the person’s own wishes, if expressed, and potentially over their rights. Although some laws, like the current ACT Guardianship Act, refer to the person’s having views and wishes that must be considered in making the decision, this obligation remains subject to the substitute decision-maker’s own view that the decision will not significantly adversely affect the interests of the person.

\textsuperscript{65} Submission 6 – Advocacy for Inclusion, page 29.
‘Best interests’ decision making is where you decide what is best for me. ‘Will, preferences and rights’ based decision making means I decide – either on my own, with support or, if I am not able to decide for a particular reason, with someone I have chosen as my representative, standing in MY shoes, not their own!

This ‘best interests’ approach has a strong paternalistic character: it allows one person to impose on another what they think is best for the other person. This is fundamentally inconsistent with the UN Convention’s principles set out in the Preamble, which recognises, in paragraph (n) the ‘importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices’. Paragraph (c) also considers ‘that persons with disabilities should have the opportunity to be actively involved in decision making processes about policies and programmes, including those directly concerning them’. It also fails to comply with Article 12(2) which requires recognition that ‘persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life’. Nonetheless it is a view deeply embedded in our social and legal cultures and practices.

Given the nature of paternalism, the best interests’ approach carries the risk that a substitute decision-maker may, consciously or not, adopt their own preference as being in the ‘best interests’ of the person. This issue has been discussed by various courts in general terms as regards the complex interrelationships between the interests of the person being cared for and the interests of the carer, and in case specific circumstances such as those relating to sterilisation of women with disabilities. The blending of interests creates vulnerability in many decision making arrangements, and can undermine supported decision making legitimacy. It was identified in NSW research as a real impediment in its Supported Decision making pilot, which is discussed further in Part 9.

Susan is a 30 year old woman with an intellectual disability. She lives at home with her parents who are her guardians. Susan has met a man with an intellectual disability at her work and she wants to have a sexual relationship with him. Her parents don’t want her to become sexually active because they are afraid she might become pregnant, so they will not allow her to be alone with her boyfriend.

The ability of a substitute decision-makers to simply make the decision can mean that they do not consider less rights-restrictive ways of addressing their concerns, nor talk to the person both about those concerns and about what options are possible. In relation to Susan’s example in the box on this page, the parents may lack the skills to explain contraception and even sexual behaviour to their daughter and they may not know someone who could. Even though there are useful resources available, they may not have access to these, and their principal concern to prevent pregnancy does not make allowance for the will, preferences and rights of their daughter to have a sexual relationship. Their view that the prevention of pregnancy is categorically in their daughter’s best interest is, at the same time, a significant restriction on her human right to seek sexual expression. This concern was raised in a Submission to the Council.

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70 Submission 11 – Women with Disabilities ACT.
4.4 Conclusions about current substitute ‘best interests’ provisions

There are inherent difficulties with substitute decision making within a ‘best interests’ paradigm.

> Most people with full capacity make decisions that are not wholly rational but have strong emotional elements. People decide on the basis of their ‘will and preferences’, consistently with their values, and within limits imposed by financial and other constraints.

> Most people with full capacity do not make decisions alone. ‘Supported’ decisions are commonplace in everyday living. As social and relational beings, people make decisions with and for others, particularly family and friends.

> People with limited or impaired decision making ability have/should have the same entitlement to make supported decisions which take account of their ‘will and preferences.’

> The blending of interests in the ‘best interests’ approach of substitute decision making creates vulnerability in such arrangements by not taking account of the supported person’s ‘will and preferences’ and thereby undermining the legitimacy of the substitute decision.
PART 5: THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Overview of this Part

The Council has been asked to consider the impact of the United Nations Convention on the Rights of Persons with Disabilities (the UN Convention), and other international human rights instruments. In the Council’s view, the UN Convention has a very significant impact on principles for guardianship and management of property in the ACT. The Council’s Report focuses significantly on the impact of the UN Convention. No other international human rights instrument adds anything of relevance, though the legal interpretation of these other instruments, recorded in the decisions of international human rights bodies, may include lessons for the interpretation of the UN Convention.

This Part sets out the background, and Australia’s approach, to the UN Convention, before describing its content and effect. Attention is paid in particular to what the UN Convention says about legal capacity and decision making.

5.1 Background

The UN Convention was adopted by the General Assembly of the United Nations on 13 December 2006.\(^{71}\) The UN Convention consolidates existing international human rights obligations stipulated under the Charter of the United Nations, the Universal Declaration of Human Rights,\(^{72}\) and the International Covenants on Human Rights\(^{73}\) in order to clarify their application to people with disabilities.\(^{74}\) It is described as the first comprehensive human rights charter of its kind in the 21st century.\(^{75}\)

5.2 Australia’s approach to its obligations under the UN Convention

When Australia signed the UN Convention on 30 March 2007 and ratified it on 17 July 2008, its ratification was subject to a declaration about its interpretation of its obligations:

- 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 UN 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;

- Australia recognizes that every person with disability has a right to respect for his or her physical and mental integrity on an equal basis with others. Australia further declares its understanding that the UN Convention allows for compulsory assistance or treatment of persons, including measures taken for compulsory assistance or treatment of persons, including measures taken for the treatment of mental disability, where such treatment is necessary, as a last resort and subject to safeguards.\(^{76}\)

Australia’s interpretive declaration can be seen as undermining its commitment to articles 12 (equal before the law), 17 (equal respect for the physical and mental integrity), and 18 (liberty of movement). This is problematic given

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\(^{76}\) Australia’s ratification of the Convention in July 2008 also included an additional reservation about its policies about entry into Australia. It states that ‘the Convention does not create a right for a person to enter or remain in a country of which he or she is not a national, nor impact on Australia’s health requirements for non-nationals seeking to enter or remain in Australia, where these requirements are based on legitimate, objective and reasonable criteria’.
the importance of these articles and their effect on the one in five Australians who are people with disabilities.\textsuperscript{77} Effectively, Australia has not wholly committed to supported decision making, and has reserved the right to use substituted decision making ‘when necessary, as a last resort and subject to safeguards’.

The UN Committee, in its response to Australia’s first periodic report under the UN Convention,\textsuperscript{78} noted the reference to the ALRC into barriers to equality before the law for people with disabilities. It expressed concern ‘about the possibility of [Australian law] maintaining the regime of substitute decision making’ and the absence of a detailed and viable framework for supported decision making in the exercise of legal capacity’. It also urged Australia to provide training, in cooperation with people with disabilities and their organisation, for ‘all actors, including civil servants, judges and social workers’ in relation to the recognition of legal capacity and the use of supported decision making.\textsuperscript{79} The Committee also raised various concerns about the deprivation of liberty of people with disabilities and the authorisation of medical treatment without free and informed consent, including involuntary treatment arrangements and restrictive practices.\textsuperscript{80} The Committee specifically urged Australia to reconsider its interpretive declarations with a view to withdrawing them.\textsuperscript{81}

It remains unclear what the precise effect of the interpretative declaration may be on Australia’s implementation of the UN Convention. However, it clearly suggested a reluctance to fully champion a shift to a rights-based approach to disability at the Commonwealth government level. In its Discussion Paper, the ALRC said that Australia’s interpretative declaration to article 12 may act as a ‘handbrake on reform’.\textsuperscript{82} The ALRC Final Report\textsuperscript{83} sought to address the concerns of the UN Committee in relation to decision making in its recommendations, as discussed in Part 6 below.

5.3 Revolutionary change

The UN Convention has fundamentally shifted the approach to guardianship law. Its preamble sets an ambitious aim:

\[\text{[t]}\text{o promote and protect the rights and dignity of persons with disabilities ... to redress the profound social disadvantage of persons with disabilities and promote their participation in the civil, political, economic, social and cultural spheres with equal opportunities, in both developing and developed countries.}\]

The UN Convention sees disability as resulting from ‘the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.’\textsuperscript{84} The UN Convention places the onus on states to overcome the extensive discrimination still faced by people with disabilities, which is often associated with poverty and exclusion. Decision making – both as an element of the individual’s autonomy and independence and in relation to policies and programs concerning people with disabilities\textsuperscript{85} – is a key focus of the UN Convention. The UN Convention also recognises the importance of family as ‘the natural and fundamental group unit of society’ that should also be protected and assisted to ‘enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities’\textsuperscript{86}

\begin{footnotes}
\item[78] Implementation of the UN Convention on the Rights of People with Disabilities, Initial reports submitted by States parties under article 35 of the UN Convention, Australia, 3 December 2010 (Australian initial response 2010).
\item[79] Committee on the Rights of Persons with Disability. Concluding observations on the initial report of Australia, adopted by the Committee at its tenth session 2-13 September 2013, CRPD/C/AUS/CO/1 21 October 2013 (UN Committee observations on Australia 2013): paragraph 24-26.
\item[80] UN Committee observations on Australia 2013 – see note 74: paragraphs 32-36
\item[81] UN Committee observations on Australia 2013 – see note 74, paragraph 9.
\item[83] ALRC Final Report 2014– see note 1.
\item[84] UN Convention – see note 66: Preamble, sub-section (e).
\item[85] UN Convention – see note 66: Preamble, subsections (n) and (c).
\item[86] UN Convention – see note 66: Preamble, subsection (x).
\end{footnotes}
The aim of the UN Convention is to ensure the full access and participation of people with disabilities in society, as reflected in its general principles set out in Article 3:

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

b. non-discrimination;

c. full and effective participation and inclusion in society;

d. respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

e. equality of opportunity;

f. accessibility;

g. equality between men and women;

h. respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The UN Convention outlines a broad range of obligations and rights, including:

- the implementation of discrimination awareness raising programs across society including within families (Article 8)
- improved accessibility to buildings, transport and other services (Article 9)
- the right to life and to humanitarian assistance (Articles 10 and 11)
- equal recognition before the law, including legal capacity and supported decision making (Article 12)
- access to justice (Article 13)
- liberty and security of the person (Article 14)
- freedom from torture or cruel, inhuman or degrading treatment or punishment (Article 15)
- freedom from exploitation, violence and abuse (Article 16)
- right to respect for physical and mental integrity (Article 17)
- rights to liberty of movement and nationality (Article 18)
- right to live independently, with whom and where they choose and be included in the community on the same basis as everyone else (Article 19)
- to have means of personal mobility (Article 20)
- the right to freedom of expression, opinion and access to information (Article 21)
- respect for privacy (Article 22)
- respect for home and family (including all matters relating to marriage, family, parenthood and relationships) on an equal basis with others (Article 23)
- right to education (Article 24); right to highest standard of health without discrimination (Article 25)
- right to comprehensive habilitation and rehabilitation to enable people with disabilities to gain and maintain maximum independence, participation and ability (Article 26)
- right to work and employment without discrimination (Article 27)
- the right to an adequate standard of living and social protection (Article 28)
- the right to participation in political and public life (Article 29), and
- the right to participate in cultural life, recreation, leisure and sport (Article 30).

Since the adoption of the UN Convention there has been a fundamental shift in the discourse on disability and the way that it is legislated. The UN Convention significantly reframes the principles which have underpinned guardianship legislation. At its core the UN Convention advocates for a shift from the ‘medical’, ‘best interest’ model utilised previously, to a social model and human rights based approach. It configures disability as complex and varying rather than as an absolute state, and recognises that people are disabled by social and environmental factors rather than their bodies alone. It obliges States to reduce social and environmental barriers through the provision of infrastructure, support and services, which promote participation and autonomy and enable accessibility and inclusion of people with disabilities. It is significant not only as a model and impetus for legislation, but also as a

87 Note the Australian Government’s reservation for this Article as well – see note 71.


powerful tool for public awareness of the difficulties faced by people with disabilities in living autonomously, and for policies that direct resources towards facilities, infrastructure and services to support people with disabilities. The UN Convention is revolutionary in reconceiving the rights of people with disabilities as deserving the same focus and commitment by governments as shown to people without disability. The key principles which underpin the UN Convention include individual autonomy, respect for dignity, independence and freedom to make one’s own choices, non-discrimination, participation and inclusion, respect for difference and acceptance of diversity, equality of opportunity and between men and women, accessibility and respect for the evolving capacity and identity of children.

Respect for autonomy presumes that all people have legal capacity, rather than presumptively assuming lack of capacity due to disability. The UN Committee on the Rights of Persons with Disabilities describes these two parts of capacity as being ‘a holder of rights and an actor under law’. The UN Convention recognises that decision making is core to exercising these rights. The nature of decision making is not independent but interdependent, and the UN recognises the reality that most people, in making decisions, consult with others for advice. It therefore views the decision making of people with disabilities similarly, which is the basis for supported decision making. It also recognises that a person’s ability to exercise their legal capacity may vary according to the decision, the decision making context, and the availability of support in the decision making. The UN Convention advocates for a transition from a ‘best interests’ substitute decision making approach to a rights-based framework, which emphasises respect for the will and preference of the individual through ‘supported’ decision making.

5.4 Underlying themes in the UN Convention

5.4.1 Equal recognition before the law

One of the fundamental principles which underpins the UN Convention is equality before the law, as reflected in Articles 5 and 12 of the UN Convention. Article 5 recognises that all people ‘are entitled without any discrimination to the equal protection and equal benefit of the law’. It follows that people with disabilities, guaranteed equal and effective legal protection, must be accorded reasonable accommodations to enjoy equality.

Article 12 outlines the right of people with disabilities to recognition as ‘people before the law’, in all contexts, equally with people who do not have disabilities. This article has been highlighted by Australian state and federal guardianship inquiries as foundational in the shift to an emphasis on the will and preferences of the individual, to more universal conceptions of legal capacity and to a paradigm shift from substituted to supported decision making.

It obliges States to ensure that they have appropriate measures in place to provide access to support that is necessary or required for people with disabilities to exercise their decision making ability, and requires states to put in place safeguards to ensure that measures relating to legal capacity do not violate international human rights law. In full, Article 12 reads:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards

90 National Association of the Deaf – see note 70.
shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of
the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s
circumstances, apply for the shortest time possible and are subject to regular review by a competent,
independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which
such measures affect the person’s rights and interests.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure
the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to
have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons
with disabilities are not arbitrarily deprived of their property.

5.4.2 Personal autonomy and self-agency

Personal autonomy and self-agency are foundational principles of the UN Convention and are reflected throughout.⁹⁴
States must ensure that laws are applied on an equal basis and that accommodations and assistance are provided
to ensure personal autonomy and self-agency. Article 13 obliges states to ensure that procedural and age-
appropriate accommodations are made to facilitate the role of people with disabilities in legal proceedings, as well as
ensuring those working in the administration of justice have been appropriately trained. Article 17 guarantees equal
respect for the physical and mental integrity of people with disabilities; article 18 guarantees liberty of movement,
and nationality; and Article 20 obliges states to ensure that people with disabilities enjoy independence and personal
mobility through measures which facilitate access and assistance.

Article 19 guarantees the right of people with disabilities to live independently and in the community, allowing all
people to carry out their lives with the same freedoms and autonomy afforded by inclusion and participation in
the community. This places a substantial obligation on states to ensure that the necessary support, assistance
and accommodations are made to allow self-agency. Article 21 guarantees freedom of expression and access
to information; states must ensure this through provision of accessible information by public bodies as well as
encouraging private entities and the mass media to deliver information in accessible and usable formats.

Throughout the UN Convention it is clear that conceptions of autonomy and self-agency extend beyond mere ‘non-
interference’, and champion ‘empowerment’.⁹⁵ This requires a significant shift in the paradigm of decision making for
people with disabilities.

5.4.3 Inclusion and participation

The social approach to disability that underpins the UN Convention emphasises inclusion and participation. This
relies on a re-conceptualisation of disability such that, ‘whilst a person might have an impairment their disability
comes from the way society treats them, or fails to support them’.⁹⁶ It follows that ensuring the social participation of
people with disabilities requires the adjustment of social and legal mechanisms.

One example of the focus on participation in the UN Convention is in article 27, which guarantees to people with
disabilities participation in and access to work and employment on an equal basis with others in the public and
private sectors. This includes freedom to work in a chosen labour market, free from discrimination relating to
disability in recruitment and promotion. States must ensure that work conditions, and remuneration allow equal
participation, and must promote employment and training opportunities as well as career advancement to people
with disabilities.

The approach is also evident in articles 29 and 30, which obliges States to ensure participation. This is clearest in
article 30, which highlights the right of people with disabilities to participate equally in cultural life through accessible
cultural materials and activities; for example, states must enable people with disabilities the opportunity to develop
their creative and artistic potential and ensure intellectual property laws do not unreasonably limit access to
cultural materials.

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⁹⁴ For example, UN Convention – see note 66: Articles 13, 14, 17, 18, 19, 20, 21.
⁹⁶ Productivity Commission. Disability Care and Support. 2011 Productivity Commission Inquiry Report No. 54, Canberra, volume 1:
page 98.
5.4.4 Accessibility

Accessibility is a key part of addressing social and environmental barriers to people with disabilities' participation and autonomy. Article 9 highlights the significance of accessibility in order to enable people with disabilities to ‘live independently and participate fully in all aspects of life’. Again, it shifts the burden to States to ensure that there is adequate infrastructure to allow people adequate access to ‘the physical environment, to transportation, to information and communications … and to other facilities and services open or provided to the public, both in urban and rural areas’. Additionally, Article 9 requires the implementation of minimum standards for accessibility of services and facilities, and the implementation of accessibility mechanisms by private entities. This includes not only physical access but also access to information and communication technologies and systems.

5.5 Decision making under the UN Convention

In its commentary on Article 12, the UN Committee has identified common substitute decision making models:

- Substitute decision making regimes can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these regimes have certain common characteristics: they can be defined as systems where (i) legal capacity is removed from a person, even if this is just in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will; and (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective ‘best interests’ of the person concerned, as opposed to being based on the person's own will and preferences.

The UN Committee is clear that substitute decision making does not comply with the UN Convention, leading to ‘States’ obligation to replace substitute decision making regimes by supported decision making’. This requires ‘both the abolition of substitute decision making regimes and the development of supported decision making alternatives’. The UN Committee warns that ‘development of supported decision making systems in parallel with the maintenance of substitute decision making regimes is not sufficient to comply with article 12 of the Convention’.

5.5.1 The exercise of will, preferences and rights under the UN Convention

The UN Convention’s recognition of individual autonomy carries with it recognition of the paramount status of a person's own will, preferences and rights in decision making. Determination by a third party of what is in a person’s ‘best interests’ is fundamentally at odds with the UN Convention.

People’s wishes and preferences create their vision for their lives and provide the colour and texture which reflects how people see themselves. Values and preferences vary among individuals, according to relationships, experiences, and social, cultural and economic circumstances. However, whether or not they have a disability, a person’s ability to give effect to their wishes and preferences is often limited because of, for example, funds, time and distance. As a result, a person with a disability will not necessarily be able to enact their wishes simply because amending legislation changes the base of decision making from ‘best interests’ substitute decision making to supported decision making based on the ‘will, preferences and rights’ of the person. A person with a disability will be subject to the same limitations that apply to every adult.

5.5.2 Impact of legacy of disadvantage for people with disabilities

For people with disabilities the ordinary limitations, to which all people are subject, are often compounded by the historic legacy of discrimination and unequal opportunities. For example, the ACOSS Report Poverty in Australia 2014,\(^99\) shows that 53% of people with a disability participated in the labour force, compared to 83% of people without a disability. This affects the incidence of households living in poverty, with 44.5% of households where someone has a disability having an income less than 60% of median household income, compared to 27.5% of all households. Additionally, over 800,000 people with disabilities receive a Disability Support Pension. Where households are dependent on the Disability Support Pension alone, more than 48% are receiving less than 50% of median household income. None of these figures takes into account the extra costs of living with a disability. Overall

\(^{97}\) UN Committee General Comment 2013 – see note 57: paragraph 23, page 6.

\(^{98}\) UN Committee General Comment 2013 – see note 57: paragraph 24, page 6.

the choices of people with disabilities are limited proportionally more than the choices of other people, because of poverty, lack of economic opportunities, and additional costs related to disability.\textsuperscript{100}

Some of these considerations can limit the ability of all people to exercise legal agency. Limited financial resources can prevent people from contracting or entering financial arrangements such as entering a mortgage to buy a house. It can mean people cannot easily pay their bills to access services. It can mean that people whose rights are violated may have limited resources to enforce those rights. Even when decision making ability for people with disabilities is dealt with in a normalised way, based on will, preferences and rights rather than on the basis of disability-based legal incapacity, it is often only a floor of equal treatment that has been established. Many other forms of inequality (mostly economic in nature) affect ability to enact wishes and exercise rights. For example, in 2014 the Australian Productivity Commission Inquiry Report noted that only about 8% of households would meet income and assets tests for legal aid,\textsuperscript{101} and commented that:

> The hard reality is that the cost of legal representation is beyond the reach of many, probably most, ordinary Australians. … In theory, access to that legal system is available to all. In practice, access is limited to substantial, business enterprises, the very wealthy, and those who are provided with some form of assistance.\textsuperscript{102}

Lack of access to services can make it difficult for someone to be ‘an actor under law’ in the words of the UN Committee but this is not a diminution of their legal capacity. Legal capacity exists and continues, whether or not it is being exercised at any particular time. The UN Convention makes clear that this is so for people with disabilities as much as for anyone: they retain their legal personhood regardless of the extent to which their ability to make decisions may be impaired.

### 5.5.3 The UN Convention and Substitute decision making

The UN Convention has played a fundamental role in advocating for a shift from substitute to supported decision making. This shift aligns with the UN Convention's core underpinnings of personal autonomy and dignity to ensure participation and inclusion in society on an equal basis.\textsuperscript{103} The Guardianship Act needs significant amendment of its substitute decision making provisions to follow the UN Convention's lead in moving away from a model of disability, which positions people with disabilities as objects of care and protection. The intention of the UN Convention is to instead provide people with disabilities with the necessary support to make decisions about their own life on an equal basis with other members of society.

The appointment of substitute decision-makers under the Guardianship Act is based on a medicalised rather than social approach to disability: ACAT determines whether a person has impaired decision making ability on a written application that is accompanied by medical, psychological or other professional reports about that person's decision making ability (Guardianship Act s 72B).\textsuperscript{104} The considerations for ACAT in appointing a guardian are only whether there is a risk to the person’s health, welfare or property, whether the person’s needs will be met, or how the person’s interests will be affected (s 7(1)).

The dualist approach of the Guardianship Act, distinguishing only between capacity and lack of capacity, fails to reflect the contextual nature of decision making ability and fails to consider the possibility of support in decision making. Once appointed, a guardian has expansive powers which deny a person autonomy and equal participation, as required by the UN Convention. The guardian’s powers extend to making decisions for that person which relate to their living arrangements, education or training, whether they can work and the nature of their employment, providing consent for medical treatment and engaging in legal proceedings (s 7(3)). The limitation on powers – that they be ‘no more restrictive of the person’s freedom of decision and action than is necessary to achieve the purpose of the order’ (s 11) – does not change the basic nature of the guardian’s power as a substitute decision-maker. To comply with the Australia’s obligations under the UN Convention, the Guardianship Act must abandon its approach of ‘best interests’ substitute decision making, and adopt a model of supported decision making.

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\textsuperscript{100} For a useful discussion on the interrelationship between poverty, the UN Convention and disability, see: Quinn G. Courtis C. Poverty, Invisibility and Disability – the liberating potential of economic, social and cultural rights. Chapter 9 in Van Bueren G. (ed) Freedom from poverty as a human right – Law’s duty to the poor. Volume 4, 2010 UNESCO Publishing, Paris (France).


\textsuperscript{102} Productivity Commission 2014 – see note 96: page 6, noting the comments of the Chief Justice of Western Australia.

\textsuperscript{103} VLRC Final Report 2012 – see note 88: page 127.

\textsuperscript{104} See also the Application for Appointment of Guardian and/or Manager and the accompanying instructions on the ACAT website: http://www.acat.act.gov.au/guardianship/guardianship_management_of_property
5.6 Changing the basis for decision making in the ACT to comply with the UN Convention

The purpose expressed in the UN Convention is:

- to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities; and to promote respect for their inherent dignity.

The Human Rights Act recognises similar rights and requires that ACT laws be interpreted in a way that is compatible with human rights. International law such as the UN Convention is not self-executing in Australian law, and needs local legislation to enable it have legal force, such as the ACT’s Human Rights Act. The Human Rights Act obliges ACT Public Authorities, including ACT Government agencies and those performing outsourced Government work, to act and make decisions consistently with human rights. Section 31 states that International law, including instruments like the UN Convention, can be used in interpreting rights. This is particularly relevant for section 8 of the Human Rights Act, which provides that everyone has the right to recognition as a person before the law, and has the right to enjoy his or her human rights without any distinction or discrimination of any kind. Section 10 also provides that no one may be subjected to medical or scientific experimentation or treatment without his or her free consent. These sections are implemented in practice by provisions that require all ACT law to be interpreted in a way that is compatible with human rights, and give people who claim that their human rights have been breached the ability to take proceedings directly to the ACT Supreme Court.

Under Article 12 of the Convention and the Human Rights Act, all people with disabilities have a right to recognition before the law and to enjoy legal capacity on an equal basis with everyone else. These provisions mean that adult people with impaired decision making ability have a right to exercise their legal capacity through making decisions with or without support, based upon their will, preferences and rights, subject to appropriate safeguards. This is based upon:

- a presumption of legal capacity;
- a recognition of their will, preferences and rights as the basis for decision making; and
- an acknowledgement that support must be provided to maximise the exercise of their ability whenever possible.

‘Substitute’ decision making is currently used in the Guardianship Act and other ACT legislation relating to people with impaired decision making ability. This provides for a ‘substitute’ decision to be made on behalf of a person with impaired decision making ability, based on the substitute decision-maker’s view about what is in that person’s ‘best interests’. To comply with the UN Convention, all relevant legislation, policy and procedure for people with impaired decision making ability must move to ‘supported decision making’, based on the will, preferences and rights of that person.

**Recommendation 1:**

The Council recommends that the ACT Government adopt a decision making paradigm for people in the ACT with impaired decision making ability that replaces a ‘best interests’-based substitute decision making model with a ‘will, preferences and rights’-based supported decision making model and that this model be reflected in legislation.

5.7 Legal capacity under the UN Convention

The concept of ‘legal capacity’ under the UN Convention has been discussed by the UN Committee on the Rights of Persons with Disabilities (‘the UN Committee’).\(^{105}\) The UN Committee makes the point that article 12, paragraph 1 recognises that:

- Every human being is respected as a person possessing legal personality, which is a prerequisite for the recognition of a person’s legal capacity.

Concerning legal capacity, the UN Committee says:

- Article 12, paragraph 2 recognizes that persons with disabilities enjoy legal capacity on an equal basis with others in all areas of life. Legal capacity includes the capacity to be both a holder of rights and an actor under the law. Legal capacity to be a holder of rights entitles the person to full protection of his or her rights by the legal system. Legal capacity to act under the law recognizes the person as an agent who can perform acts with legal effect …

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\(^{105}\) UN Committee General Comment Nov 2013, see note 57: paragraph 11, page 3.
The UN Committee explains that ‘Legal capacity and mental capacity are distinct concepts’:

> Legal capacity is the ability to hold rights and duties (legal standing) and to exercise these rights and duties (legal agency). It is the key to accessing meaningful participation in society. Mental capacity refers to the decision making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors. Under article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.

This distinction is not well-understood:

In most of the State party reports that the Committee has examined so far, the concepts of mental and legal capacity have been conflated so that where a person is considered to have impaired decision making skills, often because of a cognitive or psychosocial disability, his or her legal capacity to make a particular decision is consequently removed. This is decided simply on the basis of the diagnosis of a disability (status approach), or where a person makes a decision that is considered to have negative consequences (outcome approach), or where a person’s decision making skills are considered to be deficient (functional approach). In all these approaches, a person’s disability and/or decision making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law.

Importantly, the UN Committee states:

> Article 12 does not permit such discriminatory denial of legal capacity, but rather requires that support be provided in the exercise of legal capacity.

In light of the UN Convention’s approach to legal capacity, the current approaches to guardianship and substitute decision making are as archaic as the language of the common law relating to ‘fools natural’, ‘imbeciles’ and ‘lunatics’. This protective approach reinforces the ‘othered’ nature of people with disabilities, and as such is an instrument of their legal segregation from the rights of other adults. Many people with disabilities reject notions of state imposed ‘special’ protection and of having their ‘own good’ determined by someone else, with little or no capacity to make decisions about their ‘own good’.

It is clear from this that the language that is used is important for what it conveys and implies. In the view of the ALRC, ‘[e]ven the word ‘capacity’ carry some of the connotations of previous times. ‘Capacity’ is regularly confused with ‘legal capacity’, and ‘legal capacity’ is regularly conflated with ‘mental capacity’. The ALRC decided that, ‘[t]o avoid such confusion and to direct reform towards supported decision making’ it would use the word ‘ability’, emphasising that ‘the focus should be on assessing how the individual can be supported to exercise their ability’.

The Council advocates the use of that same language to mark this shift in emphasis. It is the Council’s view that to avoid confusion over the meaning of the word ‘capacity’ in the context of decision making, it is preferable to use instead the term ‘decision making ability’.

Because of the different uses of the words ‘capacity’ and ‘incapacity’ in different Acts, the Council considers further work is required to address this and sets out a proposal to achieve this in Part 10, recommendation 14. Appendix 2 sets out some of the other legislation which will need to be altered to ensure that the language used does not confuse the terms and makes them consistent the approach across all ACT legislation. The next section set out in broad terms the options for reforming the substitute decision making laws in the ACT to ensure compliance with the UN Convention.

### 5.7 Law reform options

Another preliminary question is how to achieve the paradigm shift required by the UN Convention. The Council’s consultations generated almost universal support in written submissions for reform consistent with the UN Convention and the ALRC Final Report. Concerns raised were not about the spirit of these reforms, but rather about how the reforms would be further developed and the need for a co-operative approach with the legal and medical profession, carers, advocates and people with disabilities, the need for a period of education and adjustment and testing of what was possible for people with significant levels of impaired decision making ability, using a supported decision making framework.

The Council has considered these concerns, and addressed them through

106 A useful discussion of the concept of the concept of determination of ‘own good’ can be found in; Arstein-Kerslake A. An empowering dependency: exploring support for the exercise of legal capacity. 2014 Scandinavian Journal of Disability Research. Available at: [http://dx.doi.org/10.1080/15017419.2014.941926](http://dx.doi.org/10.1080/15017419.2014.941926)

107 For example, Submission 16 from the ACT Law Society and Submission 13 from the Mental Health Community Coalition.
proposing a significant transition period to the generally desired endpoint of compliance with the UN Convention, as discussed later.

There has already been significant effort made towards supported decision making in a number of ACT forums, including in ACAT, in Disability ACT and in some of the work practices described by the Public Advocate’s office, and in the new Mental Health Act. There is also more pilot work on supported decision making being conducted in the ACT and elsewhere. However, these practices are ahead of the ACT law on guardianship and other substitute decision making arrangements. To broaden compliance with the UN Convention and the proposals of the ALRC, a statutory schema that is internally consistent and fit for purpose is now necessary. The Council proposes this be implemented in a staged manner, moving to a single or common statutory approach to decision making for people whose decision making is impaired.

This could occur in a range of ways:

- A single Act on Supported Decision making, of the kind recently legislated in the Irish Republic\(^{108}\) and previously legislated in England.\(^{109}\) This approach replaces the provisions of the various Acts which relate to substitute and best interest decision making, with an Act setting out the new legislative framework proposed in this Report with a cross referral to the new Act’s provisions within those;
- A common set of provisions inserted into each of the relevant Acts consistent with the framework proposed; or
- Amendments firstly made to the Guardianship Act alone, with a plan for action on the other Acts which also do not comply.

There are arguments for each of these options. The first marks a significant paradigm shift and produces legislation which could form a model for other Australian jurisdictions, all of which are considering making similar changes. It allows a single shift to occur, though there may well be options for different commencement dates for different areas. There will, of course, need to be consequential amendments to other Acts, if this model is chosen, as would be the case with any other option. However, a single Act may be seen as too big a step by some. The second option is a mid-point, which requires multiple significant changes, but which allows the continuation of known Acts, with new principles and decision making, safeguards and other provisions which are consistent across each one. The third option would be a preliminary step to later adoption of either the first or second option, as other Acts would remain inconsistent with the provisions of the UN Convention and would require amendment.

Whichever implementation option is preferred, the proposed shift in the underlying philosophy of the law on decision making in the ACT is to one which is compliant with the UN Convention and the ALRC Final Report which requires clear a legislative statement which breaks from ‘best interests’ substitute decision making. In its place there should be a system of supported decision making to give effect to a person’s will, preferences and rights, with the possibility of co-decision making when a higher level of support is required in some cases through a rights-based approach to representative decision making when no form of supported decision making is possible.

This is a significant practical and philosophical shift. This shift will require a period of transition, where the change to the law is only part of the story. A transitional period will be needed for those who are currently under guardianship arrangements or where Enduring Powers of Attorney are operative, so they and their supporters are able to make a transition to the new arrangements.

A clear statement of principle by the Government to its commitment to the UN Convention’s important goals in relation to moving from substitute decision making, based on a best interest’ paradigm, to a ‘will, preferences and rights’ based supported decision making framework is a crucial and significance first step to developing the new mechanisms and processes required to implement the change. To facilitate this transformation, the Council proposes the Government consider an exposure draft Bill, with a significant period for refinement, to address concerns, to allow education and adjustment and to establish the mechanisms that may be needed to provide administrative and practical support for these changes.

The Council’s preferred law reform option is the first – the enactment of a new overarching Supported Decision making Act which would apply to all relevant civil legislation in the ACT and consequential amendment to other legislation. As indicated, this model has recently been adopted in the Irish Republic in its Assisted Decision-Making (Capacity) Act 2015. If this option is not accepted, the Council recommends the second option for the insertion in all

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108 Assisted Decision-Making Capacity Act 2015 (Irish Republic): this Act uses a will, preferences and rights supported decision making approach.
109 Mental Capacity Act 2005 (UK): while this legislation provides an integrated framework, it retains best interest substitute decision making.
relevant ACT legislation of a standardised model of supported decision making, consistent with the recommended policy change. If neither of these two options is accepted, the Council proposes implementation of its third option – the insertion in the Guardianship Act of a statutory model of supported decision making consistent with the change of policy and principles recommended above. However, this last option will leave a number of other significant Acts non-compliant with the UN Convention and with the ACT Human Rights Act. With all these options, there are likely to be consequential amendments involving other legislation.

**Recommendation 2:**

The Council recommends that legislation to implement the new ‘will, preferences and rights’-based supported ACT Decision making Framework be prepared for public consultation, using one of the following options in order of preference:

2.1 A single Act providing for the overarching reform of the law relating to people who require or may require assistance in exercising their decision making ability to mandate the use of the ‘will, preferences and rights’-based supported decision making framework; or

2.2 The use of a ‘will, preferences and rights’-based supported decision making framework be independently inserted in all existing legislation that currently provides for substitute decision making for people who require or may require assistance in exercising their decision making ability; or

2.3 A ‘will, preferences and rights’-based supported decision making framework for people who require or may require assistance in exercising their decision making ability, be inserted in the *Guardianship and Management of Property Act 1991* in place of the current ‘best interest’-based substitute decision making provisions.
PART 6: THE ALRC’S PROPOSALS AND THE GUARDIANSHIP ACT

6.1 The ALRC Reference

As noted in Part 1, the ALRC Final Report Equality, Capacity and Disability in Commonwealth Laws was tabled on 24 November 2014, just prior to the commencement of the Council’s reference. The ALRC Terms of Reference, given in July 2013, asked that, in light of the UN Convention, the ALRC inquire into and report on:

The examination of laws and legal frameworks within the Commonwealth jurisdiction that deny or diminish the equality recognition of people with disability as persons before the law and their ability to exercise legal capacity;

The scope of its reference was much wider than the Council’s reference, as it covering ‘all relevant Commonwealth laws and legal frameworks that either directly or indirectly impact on the recognition of people with disability before the law and their exercise of legal capacity on an equal basis with others’.

The areas included: access to justice and legal assistance program, administrative law, aged care, anti-discrimination law, board participation, competition and consumer law, contracts, disability services and supports, electoral matters, employment, federal offences, financial services including insurance, giving evidence, holding public office, identification documents, jury service, marriage, partnerships, parenthood and family law, medical treatment, privacy law, restrictive practices, social security, superannuation and supported and substitute decision making.

Among a range of propositions, the terms of reference asked the ALRC to explore ‘how maximising individual autonomy and independence could be modelled in Commonwealth laws and legal frameworks’.

Of specific importance to the work of the Council was its recognition that many laws which impacted on the rights of people with disabilities were under state and territory control. Recommendation 10-1 in the ALRC Final Report stated:

State and territory governments should review laws and legal frameworks concerning individual decision making to ensure they are consistent with the National Decision making principles and the Commonwealth Decision making Model. In conducting such a review, regards should also be given to:

a. interaction with any supporter and representative schemes under Commonwealth legislation;

b. consistency between jurisdictions, including in terminology;

c. maximising cross-jurisdictional recognition of arrangements; and

d. mechanisms for consistent and national data collection.

It was this recommendation, with the sense of moving towards a nationally consistent approach to supported decision making that led the Council to use the ARLC’s proposals as the starting point for consultations.

6.2 ALRC Framing Principles and the UN Convention

General principles express the theoretical approach that underpins guardianship legislation. Decision making principles provide practical direction so that those who are performing a function or power under the Act do so consistently with the underpinning theoretical approach.

General principles are a feature of the UN Convention, in article 3, set out above in Part 5. General principles also characterise the reform directions taken by law reform bodies in Australia. The Queensland Law Reform Commission (QLRC), for example, proposed amendment to the General Principles and Decision making Principles in various substitute decision making Acts in recognition of the principles of the UN Convention. Some key principles articulated by various law reform commissions include the same human rights and fundamental freedoms as people

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who do not have disabilities, support to participate in and carry out decisions, empowerment to exercise human rights and fundamental freedoms, entitlement to participate in community life, maintenance of existing supportive relationships and cultural and linguistic environment and values, respect for privacy, entitlement to take reasonable risks, and maximising an adult’s participation in decision making. The Victorian Law Reform Commission (VLRC) also stated that any limitation on these freedoms must be ‘justified, reasonable and proportionate’.

It is the Council’s view that the current Guardianship Act does not set out general principles that comply with the UN Convention Principles and that the other substitute decision making legislation in the ACT includes different and conflicting principles. These deficiencies can be overcome by having a single set of principles in the single decision making ability Act proposed, or if not a single Act, a common set of principles across each one.

The ALRC Final Report bases its recommendations on what they call ‘five framing principles’:

- Dignity
- Equality
- Autonomy (in the sense of empowerment, rather than non-interference)
- Inclusion and participation, and
- Accountability.

The ALRC sees these as key parts of both the UN Convention and the National Disability Strategy 2010-2020, endorsed by Commonwealth, State and Territory Chief Ministers through the Council of Australian Governments on 13 February 2011. These principles are also reflected in the legislation underpinning the NDIS Act. In the ACT, these same principles are reflected in the human rights principles to be furthered under Schedule 1 of the Disability Services Act 1991 (ACT), and in the rights enacted in the Human Rights Act.

The Council considers these framing principles to be a useful guide for the proposed legislation on decision making ability. They provide principles against which different options that might be developed under the general enabling legislation, proposed for supported decision making, might be measured. They also serve as a guide to the directions proposed by the ALRC for a National approach and are supported by both the UN Convention and other international human rights instruments.

6.3 Decision making principles

The current Guardianship Act (s 4) sets out principles to be followed by substitute decision-makers, rather than principles that enable and support a person with a disability to make their own decisions, and ensure that those decisions are respected. The principles clearly operate from a best-interests framework; they are not based on a commitment to autonomy, equality before the law, participation and inclusion, and they fail to promote the independence of people with disabilities. For example, the Guardianship Act sees decision making as the domain of a carer and substitute decision-maker. But where a person must be supported and enabled to make decisions for themselves it is insufficient to merely ‘consult with each carer of the protected person’ before making a decision (s 4(3)). Although the Guardianship Act requires that a person’s wishes must be ascertained as ‘far as they can be worked out’, their wishes will not be given effect if they are ‘likely to significantly adversely affect’ the person’s interests (s 4(2)). And rather than encouraging people to live in the general community and participate in community activities ‘as far as possible’ the Guardianship Act should express the right to such participation and require necessary support to ensure this is achieved.

116 Reflects Articles 3(a) and 12(4), UN Convention – see note 66.
117 Reflects Articles 3(c) and 12(4), UN Convention – see note 66.
119 VLRC Final Report 2012 - see note 88: page 94.
122 Guardianship Act, section 4(2)(f).
6.3.1 The ALRC’s National Decision making Principles

The ALRC Final Report sets out four National Decision making Principles, to ensure that supported decision making is encouraged, that representative decision-makers are appointed only as a last resort, and that people’s will, preferences and rights direct the decisions that affect their lives.

The four National Decision making Principles are:

- Principle 1: All adults have an equal right to make decisions that affect their lives and to have those decisions respected.
- Principle 2: People 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, and
- Principle 4: There must be appropriate and effective safeguards for people who may require decision making support, including to prevent abuse and undue influence.

6.3.2 The Principles for Reform

A simple, concise statement of principles should be adopted which affirms and provides the basis for this paradigm shift. The Council recommends the broad framing principles for reform of laws relating to people with disabilities recommended in the ALRC Final Report for this purpose. These principles are dignity, equality, autonomy, inclusion and participation, and accountability.

In the context of reform of decision making arrangements for people with impaired decision making ability, the Council’s consultations also showed broad support for the ALRC’s National Decision making Principles. The Council considers that these principles provide a sound basis for reform of decision making laws in the ACT.

Recommendation 3:

The Council recommends that the ACT’s reform of law and policy relating to decision making arrangements for people with impaired decision making ability be based upon the Australian Law Reform Commission’s four National Decision making Principles:

- Principle 1: All adults have an equal right to make decisions that affect their lives and to have those decisions respected;
- Principle 2: People 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; and
- Principle 4: There must be appropriate and effective safeguards for people who may require decision making support, including to prevent abuse and undue influence.

6.4 The ALRC Guidelines

The ALRC set out three sets of Guidelines to support these Principles. The first of these are Support Guidelines:

Support Guidelines (Recommendation 3-2)

1. General
   a. Persons who require decision making support should be supported to participate in and contribute to all aspects of life.
   b. Persons who require decision making support should be supported in making decisions.
   c. The role of persons who provide decision making support should be acknowledged and respected, including family members, carers and other people chosen to provide support.
   d. Persons who require decision making support may choose not to be supported.
2. **Assessing support needs**

In assessing what support is required, the following must be considered:

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

b. A person must not be assumed to lack decision making ability on the basis of having a disability.

c. A person’s decision making ability must be considered in the context of available supports.

d. A person’s decision making ability is to be assessed, not the outcome of the decision they want to make.

e. A person’s decision making ability will depend on the kind of decisions to be made.

f. A person’s decision making ability may evolve or fluctuate over time.

The second set are Will, Preferences and Rights Guidelines for both supported decision making and representative decision making:

**Will, Preferences and Rights Guidelines** (Recommendation 3-3)

1. **Supported decision making**

   a. In assisting a person who requires decision making support to make decisions, a person chosen by them as supporter must:

      (i) support the person to express their will and preferences, and

      (ii) assist the person to develop their own decision making ability.

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

      (i) communicate by any means that enable them to be understood, and

      (ii) have their cultural and linguistic circumstances recognised and respected.

2. **Representative decision making**

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

a. The person’s will and preferences must be given effect.

b. When 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 the person’s life.

c. If it is not possible to determine what the person would likely want, the representative must act to promote and uphold the person’s human rights and act in the way that is least restrictive of those rights.

d. A representative may override the person’s will and preferences only where necessary to prevent harm.

The third set of guidelines are for safeguards, both to ensure that the human rights of a person with a disability are protected, and to protect someone’s decision making from exploitation:

**Safeguards Guidelines** (Recommendation 3-4)

1. **General**

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

a. the least restrictive of the person’s human rights

b. subject to appeal, and

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

   The ALRC also highlights the significance of language and terminology in the context of disability, as discussed earlier.

   The Council received almost universally positive feedback in submissions and at consultation meetings about the ALRC Decision making Guidelines, including from people who were subject to guardianship at the moment. The Council considers that the National Decision making principles and Guidelines provide a useful rubric upon which to base nationally consistent arrangements for those who have impaired decision making ability. Accordingly, the Council proposes that these be used as the underlying principles for the single legislative framework noted in Recommendation 1, to ensure compliance with the UN Convention, and adapted— as far as is necessary — for the ACT environment.

6.4.1 Decision making guiding principles

The ALRC Guidelines provide sets of strong philosophical and practical guidance for new legislation, policy and procedures. They also provide a useful basis for a nationally consistent approach to decision making for people with impaired decision making ability. The Guidelines received strong community support for these Guidelines in submissions to the Council.

**Recommendation 4:**

The Council recommends that the development of legislation, policy and procedures to implement the new ACT Decision making Framework be informed by the principles in the Australian Law Reform Commission's Guidelines on ‘Support’; ‘Wills, Preferences and Right’; and ‘Safeguards’.

6.5 The ACT Decision making Framework

The Australian Law Reform Commission recommended that support be made available for people who needed assistance to exercise their decision making ability in the form of supported decision making. In cases where this was not possible, the Australian Law Reform Commission proposed there be representative decision making. In both circumstances, the decision making would be directed by the will, preferences and rights of the decision-maker. The Council was persuaded by the work of other law reform agencies in Australia and overseas that there was also a place for co-decision making as an additional form of supported decision making in appropriate circumstances. A new decision making framework based on these three forms is recommended.

**Recommendation 5:**

The Council recommends that the ACT’s new framework for supported decision making provide for three forms of assisted decision making:

5.1 **Supported decision making:** The decision making framework requires and provides support for decision making based upon the will, preferences and rights of someone whose decision making ability is impaired.

5.2 **Co-decision making:** Where impaired decision making ability makes the exercise of decision making ability with support difficult, additional support shall be provided to allow the person to properly exercise their decision making ability.
5.3 Representative decision making: Where it is not possible to provide sufficient support for a specific decision by a person with impaired decision making ability, any method chosen to make that decision must be representative of the will and preferences of the person with impaired decision making ability, as well as being consistent with their rights.

This Framework is expanded in the following Parts.
PART 7: SUPPORTED DECISION MAKING AND RELATED MECHANISMS

Overview of this Part

The most significant implication of the UN Convention for guardianship in the ACT is the necessary shift from substitute decision making to supported decision making. This Part describes the nature and implications of supported decision making in the ACT context, and further details about the ACT Decision making Framework.

7.1 Supported decision making

Decision making is integral to the exercise of legal capacity, hence the Council’s preference – reflecting that of the ALRC – for the term ‘decision making ability’ in place of ‘capacity’.

Based on the presumption that every person has decision making ability, Article 12(3) of the UN Convention requires state parties to ‘take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity’. To give effect to this in Australia, the ALRC’s National Decision making Principles state:

- 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.

Supported decision making is a method where another person – commonly family members and friends, but also health and welfare professionals and dedicated decision making supporters – assist people with disabilities in making their own decisions which reflect their individual will and preference. This formalises what is already often a ‘family shared process’ of decision making. Supported decision making also reflects current practice for most people in the community where decision making involves engagement with and advice from others in everyday life.

In the evaluation of a supported decision making pilot in NSW, supported decision making was defined as ‘the process of assisting a person with disability to exercise their legal capacity to act on an equal basis with others’. Significantly, this definition links decision making to the principle of universal adult legal capacity, and shows how supported decision making assists in establishing legal agency, the ‘action’ part of legal capacity.

The role of a supporter depends on the level of decision making ability of the person being supported. It may include providing or explaining information in an accessible format, assisting the person to consider their options and the consequences of options, providing advice, assisting a person to effectively communicate their decisions and ensuring that such decisions are respected.

Barriers to the exercise of decision making ability can be acute for people with certain disabilities, such as people who are experiencing the effects of a delusional psychosis, people who have dementia, people who experience episodic psychosocial disabilities, and people with an intellectual disability. However, it is likely that all these people have some decision making ability, particularly if they are allowed to practice the necessary skills, so the need for support in their decision making is crucial to give full expression to their will and preferences.

123 ALRC Final Report 2014—note 1; see page 64 and pages 67-69.
124 McCallum R. 2014 – see note 72.
129 In all of the Australian supported decision making pilots to date, preparation of people requiring support for their decision making so they were ‘decision-ready’ was seen as crucial. Issues identified which can affect this are limited literacy and communication skills and lack of confidence. See, eg, NSW SDM Pilot Report 2015 – see note 62: pages 66-67
The concept of ‘supported decision making’ is already promoted in some ACT legislation, such as the Mental Health Act discussed in Part 3, and the Disability Services Act 1991 (ACT), the last of which states that:

People with disabilities have the same right as other members of society to make and actively participate in the decisions that affect their lives and are entitled to appropriate and necessary support to enable participation in, direction and implementation of the decisions that affect their lives.\(^{130}\)

At the heart of reform to the ACT laws on guardianship, therefore, must be a commitment to ‘assisting a person with disability to exercise their legal capacity to act on an equal basis with others’.

### 7.1.1 Challenges with supported decision making

Although the shift to supported decision making is necessary to uphold the equal human rights of people with disabilities in line with the UN Convention, the practical hurdles associated with this task are significant. Supported decision making requires significant time and resources to enable people of varying levels of decision making ability to direct the decision making in their own lives. It is likely this process would be easier to operationalise in circumstances where a person has intermittent impairment to their decision making ability. In these instances, decisions could be made when that person’s decision making ability is least ‘impaired’. By comparison, where a person has progressive impairment of their decision making ability, such as can occur with dementia-related diseases, this may be more difficult.

The VLRC noted in 2012 that there were concerns in relation to the implementation of supported decision making.\(^{131}\) First, supported decision making would add complexity to legal arrangements. Secondly, there is limited experience of this model in other jurisdictions. Finally, formalising this process may undermine existing informal support, which is in place and effective.\(^{132}\) These concerns are being addressed through the various completed and on-going pilots of supported decision making, some of which are discussed in Part 9 above. It is important that these concerns are considered in the transition period and in the context of legislative change.

Furthermore, the possibility of shifting to a supported decision making model is complicated by Australia’s current interpretive declarations, particularly in relation to Articles 12. In this declaration the Australian government outlined its view that substituted decision making may still be a necessary component of guardianship processes in Australia. The operation of the ACT’s Human Rights Act requires the ACT Government to separately review the compliance of its legislation with the rights in that Act and in international human rights obligations. This means that the ACT Government can act to ensure its legislation is compliant with the UN Convention, regardless of the Commonwealth’s interpretive declaration. In any event, the ALRC proposal for a will, rights and preferences regime as discussed in Recommendation 5, is seen as addressing the major concerns of the UN relating to Australia’s approach to substitute decision making.

### 7.1.2 Assessment of the need for support in decision making

**The current Guardianship Act and determining ‘incapacity’**

Contrary to the UN Convention, the Guardianship Act makes no presumption of capacity. Such a presumption is required by article 12 and is essential to any assessment of decision making ability under guardianship legislation.\(^{133}\) Further, the Guardianship Act approaches a determination of decision making ability as a singular and absolute decision, rather than as one that is context and decision-specific.\(^{134}\) The Guardianship Act also draws a ‘convenient but artificial distinction’\(^{135}\) between people who possess decision making ability and those who do not, while the UN Convention calls for a more nuanced approach, which recognises that even people with significantly impaired decision making ability people can generally make decisions in some parts of their lives. All of these differences will impact on the type of assessments required under the new system.

\(^{130}\) Disability Services Act 1991 (ACT), Schedule 1 – Human Rights principles to be further in relation to people with disabilities, principle 5.

\(^{131}\) VLRC Final Report 2012 - see note 88: page 136.


\(^{133}\) Article 12 UN Convention – see note 66 .

\(^{134}\) VLRC Final Report 2012 - see note 88: page 122.

\(^{135}\) VLRC Final Report 2012 - see note 88: page 39.

62 ACT Law Reform Advisory Council
Prior to the release of the ALRC Final Report, the Queensland Law Reform Commission (QLRC) supported a functional approach to determinations of legal capacity. The QLRC identified that this approach aligned with the presumption of decision making ability, emphasised the context and decision specific nature of decision making and therefore ‘maximise[d] their decision making autonomy by enabling the adult to continue to make decisions in those areas of life for which they have capacity’.\(^{136}\) This approach was premised on the functional ability of people to make a specific decision at a specific time, focusing on an individual’s ability to understand and assess information relating to the specific decision.\(^{137}\) A focus on determination of decision making ability in a context and decision specific manner may have significant practical and resource consequences, given that different standards of decision making ability are sometimes required under different areas of the law.\(^{138}\)

Appreciating that decision making ability is fluctuating and decision-specific, the VLRC and ALRC recommend principles for determining decision making ability, based on the NSW Capacity Toolkit.\(^{139}\) Importantly, decision making ability is assessed having regard to appropriate support and by addressing of limiting environmental factors.

The QLRC stated that there are practical challenges in implementing, both the definition and assessment of decision making ability and they considered that comprehensive guidelines concerning the definition of decision making ability and its application are essential to ensure a correct and consistent approach.\(^{140}\) The application of the presumption of decision making ability is another issue, which the QLRC also considered. They suggested an approach for the application of presumption following concerns from the Public Trustee, whose role is predicated on a prior decision by the Guardianship and Administrative Tribunal that a person lacks decision making ability.\(^{141}\) The Commission outlined that the presumption is applied once for specific types of decisions. If the presumption has already been qualified by the Tribunal or Supreme Court for specific kinds of decisions and a guardian or administrator has been appointed, the guardian or administrator does not have to apply the presumption themselves – they can rely on the rebuttal of the presumption for that matter.\(^{142}\) However, where a formal declaration of capacity has not been made, the guardian must apply the presumption. Since decision making ability is to be considered in a context and decision-specific manner, the presumption will not be displaced for other matters, even where the Court has already determined lack of decision making ability for a specific matter or type of matter.\(^{143}\)

It is arguable that guidelines, of the kind proposed by the QLRC, undercut the UN Convention’s intention that wherever possible, someone will be supported to make their own decisions and further do not comply with the ALRC’s own proposals. Significant time will be required to determine ability on an individual basis in each specific context and type of decision the extent of that an individual’s decision making ability. However, these concerns may be relieved by understanding that the goal has shifted from a single determination of ability or capacity, to determining a process of support to help exercise ability in as many decisions that the person wishes to make, subject to safeguards discussed below. Where the focus is on ‘support needed’ at any particular time, the issues are different from the capacity or ability assessments required under the current legal system.

### Assessing support needs

Under the UN Convention, all adults are presumed to have legal capacity, which includes the ability to make decisions. At some stage in a person’s life a question as to their decision making ability may arise, and an assessment of their decision making ability and support needs may be required. Because of its nature, this assessment will be significantly different from the old assessment of incapacity and may well involve different assessors and assessments. Given the paradigm of the new system, the ‘assessment’ will be likely to produce ‘enabling’ guidelines within a determined framework, rather than a set of status determinations, in most cases.

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138 VLRC Final Report 2012 - see note 88: page, 102
142 QLRC Final Report 2010 – see note 88: page xiv
The ALRC sets out in some of its recommendations a method of determining whether someone’s decision making ability in relation to a particular decision is impaired, so that they require support. This is done by assessing whether someone can:

- understand the information relevant to the decision they have to make;
- retain the information necessary to make the decision;
- use or weigh the information as part of the decision making process; and
- communicate their decision in some way.\(^{148}\)

For young people with intellectual disabilities or psychosocial disabilities, an assessment may have occurred in their pre-adult years, especially if they attended a ‘special school’. Over time, it should be expected that younger people who are not yet adults will be assisted to learn about the steps of decision making. This is something that would be likely to be helpful to all children and young people, but it may be especially important for those who previously have been seen as likely to lack decision making ability. Under a new paradigm, where legal personhood is universal, it would be expected that support would be provided to maximise the potential for everyone to become a decision-maker when they are an adult. Training in decision making would be a precursor to decision-readiness and would form part of the education of all children and young people, especially those who may need support in one or more areas.

For adults, the assessment of decision making ability under current arrangements may have occurred later. It may have been done by a geriatrician or by an Aged Care Assessment Team assessor, when the person needed support services to stay in their home or to move to supported accommodation. For people with mental illness or other psychosocial disabilities, the assessment may have occurred at a time of a health crisis, when a doctor, court or tribunal was also involved. Such assessments are usually about a person’s ‘capacity’, identifying a deficit in capacity that will be addressed by a substitute decision making arrangement. However, the alternative presumption of capacity will mean that an assessment must be made of the level and nature of support that the person needs to exercise their decision making ability in accordance with their will and preferences. Such assessments will require quite different processes and skills.

Assessments about decision making ability in the form of what is in someone’s ‘own good’ are embedded in the values and perceptions of reality of the assessor. In the important book Capacity to decide,\(^{145}\) the authors discuss in some detail how the assessor’s own views can significantly affect conclusions that are reached about the person. Many of these views are ‘unexamined, unchallengeable beliefs, hypotheses and values that are simply accepted and usually excluded from dispute’.\(^{146}\) For example, if an assessor has a presumptive belief that a person with dementia is unable to make any decisions and needs to be ‘protected’, they are likely to see only the evidence that supports this view, and may argue that allowing the person to make some decisions is too dangerous. Similarly, an assessor may believe that someone with an intellectual disability cannot make ‘good’ decisions. If they see a person with an intellectual disability makes a decision with a bad outcome, they are likely to conclude that the person should not in future be allowed to make decisions which involve risk, this fails to take account of the fact that most people may make a ‘bad’ decision at some point, particularly when learning.

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**People who want to make change by presenting alternate accounts [of reality] challenge and threaten those who hold power. Those in power attempt to protect and promote their beliefs and values. Those who try to bring about change by presenting alternate accounts risk institutionalised intolerance and punishment.**


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The characterisation of the outcome of a decision as good or bad can also be a subjective decision, based on values. For example, an older person living in assisted accommodation may wish to have a consensual sexual relationship with someone else who lives there. A staff member may prevent the person doing what they wish...
because the staff member does not consider it appropriate according to their own values. Similarly, families may prevent the person doing what they wish because the family does not see their elderly relative as a sexually active person, or they believe that their relative is too confused to give consent, or they fear that such a relationship will disrupt their family dynamics.

Supported decision making is conversely driven by the person’s will, preferences and rights, not by another’s decision as to the person’s ‘best interests’. As such the values reflected in the decision should be the person’s own. Assessment practices therefore need to focus on identifying the ability the person has to work out their will and preferences and to express them, as well as what decision making abilities that the person has, which can then be developed and supported.

Rather than drawing directly on previous models of capacity assessment, new methods of assessing the degree of impairment of decision making ability and the kind of support required, will be needed. These will need, among other things, to determine whether the need for support is critical for the exercise of the person’s decision making ability generally or specifically to certain decisions. The ALRC Final Report’s four ‘skills’ for decision making set out above: understanding necessary information, retaining the information to make the decision, considering the information and making the decision; provide some guidance about the type of assessment needed. Assessments will need to focus on what would be required to support people to exercise their decision making ability.

The Swedish Personal Ombudsmen system, for example, uses the Camberwell Assessment of Need Model, which is a clinical and social needs assessment instrument for people with severe mental illness. They place importance on the instrument but say the tool is less important than having an effective way of identifying the support needs (and the will and preferences) of the person, which is, in fact, what the UN Convention requires.

It is the Council’s view that the move to supported decision making is likely to be particularly challenging to those who have exercised and are currently exercising power under a substituted decision making arrangement. To ensure a successful shift to supported decision making, it is likely that supporters will require training about the nature of these changes and the necessary change to the power dynamics which may have existed under a best interests, capacity-based, substituted decision making model. Accordingly, the Council proposes a transition period, when options for assessing the levels of support needed for decision making should be tested. Those in a position to assess a person’s need for decision making support will require training about the new regime and the necessary changes to assumptions, attitudes and power dynamics that exist under a substituted decision making model. There should be a transition period for moving from substitute decision making to supported decision making, which would involve the development of an assessment method to determine what supports someone may require to exercise their decision making ability including education and training to become ‘decision-ready’, skill development for different types of decisions, monitoring and safeguards.

7.2 How to support decision making

As outlined, the kinds of support that might be required to assist people to make decisions in their lives are many and varied, and may vary over time and with the kind of decision. The necessary decision making support could be as simple as reducing environmental and physiological impediments to decision making to ensure that a person has the best conditions to make decisions, for example by ensuring they are in a quiet room with someone they trust, that they have a drink, and are not rushed. In other cases, a person may be better able to make decisions in the morning, or after a meal.

7.2.1 Reasonable accommodation and adjustments

The necessary decision making support could require reasonable adjustments or, in the words of the UN Convention, the making of ‘reasonable accommodation’ to how things are ordinarily done. For example, if someone cannot read text because of a vision impairment, then the person will need someone to read information to them, or to have access to an appropriately formatted document for a machine reader. If someone has an intellectual disability, they will need a longer time to make a decision and they will need a simple English explanation of what the

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particular decision means. This is a concept well established in the ACT’s Human Rights Act and its administration. It is also a general requirement under Article 5 of the UN Convention relating to equality and non-discrimination:

In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

Article 2 defines reasonable accommodation as:

necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

Decision making is a contextual process and the existence of accessible information in appropriate formats and social supports can enhance a person’s capacity to make decisions.

Advocacy for Inclusion, Submission 6, page 29

Having access to comprehensible information has been identified as important in ensuring people have access to services. For example, health services recognise that it is best practice for all people in our community to be provided with ‘plain English’ health information, and it is increasingly common to provide translated material for people from culturally and linguistically diverse backgrounds. Significant resources are committed to providing more easily understandable information and legal documents, such as contracts. Decision making support requires the same approach to ensure that information is available in accessible styles and formats. The Council’s conduct in its inquiry made an effort in this direction, publishing an ‘Easy English’ consultation document and making a brief video to explain the nature and process of the inquiry. Submissions received from people with disabilities often involved a supporter working with the person to help them express their views.

The recent evaluation of supported decision making pilot in NSW found that much of the written material, prepared as part of the pilot to support decision making, provided very limited assistance to the decision-makers and their supports. The materials had been considered very useful by the facilitators, but supporters and decision-makers found the materials overwhelming unless they had assistance from the facilitator. This appeared partly to do with low literacy levels among decision-makers and partly to do with how the tool kit was presented. An exception was the Easy Read booklet, ‘which appeared to serve as a focal point and added legitimacy to the supported decision making process for some decision makers’.

The booklet was used by both decision-makers and supporters to


150 See for example: Australian Commission on Safety and Quality in Health Care. Consumers, the health system and health literacy: Taking action to improve safety and Quality. Consultation Paper June 2013: see especially pages 26-29.

151 The Australian Charter of Public Service in a Culturally Diverse Society, agreed between the Commonwealth Government and State and Territory Governments in 1998, identified quality client services as requiring access to information about the services provided by Government through the availability of language assistance and interpreters, and noted the need to address the ‘double disadvantage faced by indigenous or ethnic women, youth, older persons and disabled people, when seeking access to government services’. See also Jonas W. On the Sidelines – Disability and People from Non-English Speaking Background Communities. Human Rights and Equal Opportunity Commission 2000: see especially good practice examples, listed on page 57 and conclusions on pages 58-61. See also: Zanchetta M. Pourebslami IM. Health literacy within the reality of immigrants’ culture and language. 2006 Canadian Journal of Public Health, May-June, volume 97 Supplement 2, pages S26-S30.

152 Efforts to produce more comprehensible and ‘easy to understand’ legal documents have a long history in Australia. See, eg, Butt P. Speaking Plainly: Plain language law for non-lawyers, 2002: http://www.plainlanguage.org. See also the work of the Law and Justice Foundation of NSW at http://www.lawfoundation.net.au/information.

153 NSW SDM Pilot Report 2015 – see note 62: page 74-75, where suggestions for modifications to the kit were made eg Factsheets, using the web etc.

“keep them on track and to explain the process.”\textsuperscript{155} In particular, the Pilot recommended such resources, in future, be tailored to individual circumstances, developed with relevant therapists, and with those closest to the decision-maker.\textsuperscript{156}

Re-worked processes by services and institutions can provide the necessary support to people with impaired decision making ability. For example, a recent publication produced by Family Planning NSW helps doctors work with clients with intellectual disabilities on issues of reproductive and sexual health,\textsuperscript{157} changing how they might conduct a consultation to allow the person more time, and a safer place to have these sensitive discussions. Another similar Australian resource for professionals working with people with intellectual disabilities who have been harmed by violence is How to hear me.\textsuperscript{158} Organisations that usually interact with people with impaired decision making ability through a substitute decision-maker, such as courts, tribunals, hospitals and some service providers and professionals, will require some significant and creative rethinking of many of their processes to enable supported decision making with proper regard to the will, preferences and rights of the person to take place. The transformative work of the National Disability Insurance Agency in establishing individualised funding for people with disabilities, based on self-determined plans whenever possible, provides some early experience of success with seeking to create more responsive institutional environments for people with disabilities to make decisions\textsuperscript{159} This model is based on a social model of disability that recognises ‘attitudes, practices and structures are disabling and can prevent people from enjoying economic participation, social inclusion and equality’.\textsuperscript{160}

Barriers to enacting decisions can also be physical, such as inaccessible buildings or the lack of means to exercise power. A person may want to vote and be able to decide who to vote for, but they may have trouble accessing a polling booth or using the normal means of voting. As well complex processes can make enacting a decision difficult, for example starting a bank account or filling out application forms for jobs or services.

### 7.2.2 Capacity building

The necessary decision making support, particularly for people who have limited experience of making decisions, will require capacity building. This can be done through various forms of training and practice, teaching the process of decision making and modelling it with the person, allowing the person to work on simple low risk decisions first while they develop their skills, then working towards a time when they may be able to make decisions without support.

As is detailed in the pilot descriptions in Part 9, many of the pilots of supported decision making in Australia and overseas have shown that capacity building has been a crucial transitional requirement. For example, training has been crucial to allow people with disabilities, who have not been involved in many choices about their lives, to be able to make service choices under the NDIS.\textsuperscript{161} Processes that have been trialed to provide specific decision making support include computer assisted decision supports\textsuperscript{162} and the use of mobile apps.\textsuperscript{163} These provide information about where to get advice and allow people to go through a structured decision making process, by themselves or with a supporter, to make and record the decision, and to record the actions that are necessary to enact their decision.

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\textsuperscript{156} NSW SDM Pilot Report 2015 – see note 62: page 75.

\textsuperscript{157} Family Planning NSW 2015 – see note 63: see especially Tips for Communication.

\textsuperscript{158} WWILD Sexual Violence Prevention Association Inc Disability training Program – Victims of Crime. How to hear me: A resource kit for counsellors and other professionals working with people with intellectual disability, 2012 funded by the Department Justice and Attorney General (Queensland) Building Capacity for Victims of Crime Services Funding Program.

\textsuperscript{159} See eg Advocacy for Inclusion. Ask me. I make my own decisions – Report on the findings of a study into the experience of control and choice of people with disabilities in the ACT, May 2013: This Report looks at the situation of people with disabilities at the beginning of the National Disability Insurance Scheme (NDIS) implementation in the ACT, about the readiness of people with disabilities to exercise control and choice over their own lives and supports, which are central underpinnings of the NDIS.

\textsuperscript{160} COAG 2011 – see note 116: page 16

\textsuperscript{161} In its 2013 report on the control and choice of people with disabilities discussed in note 154, Advocacy for Inclusion discussed the Planning Alternative Tomorrows with Hope (PATH) program, which was available in the ACT to help people to work out what they wanted for themselves and their life.

\textsuperscript{162} ADACAS has developed the web-based tool: http://www.support-my-decision.org.au/. Once a user registers they can keep records of their decision making processes and access them at a later date to complete or re-consider.

\textsuperscript{163} ADACAS has developed a mobile app for the iPad called Supported Decision making, which is available from the IOS App Store for $A9.99.
Training for people who will provide decision making support is also required, and the NSW pilot suggests that individualised training with supporters and the person they were supporting is more helpful and effective than group training. Other pilots discussed in Section 9 show that many people with disabilities who were considered unable to make decisions showed significant improvement in their decision making capacity over the period of the trials.

7.2.3 Approaches to giving support

… supported decision making arrangements are not something that can be imposed on a person or the people supporting them. It is imperative that people with disabilities remain in control of whether (and in what manner) they wish to engage with support in making decisions.

Advocacy for Inclusion, Submission 6, page 30.

The focus of supported decision making is on helping the person to work out what they want to do based on their own will and preferences. There are many different ways support can be provided for this, and it is important that the person can choose the supports which work best for them. This can vary between types of decisions. Many people with impaired decision making ability are able to make some decisions themselves, particular in relation to everyday choices regarding, food, clothing, entertainment and so on. However a person may need support to make an important or complex decision, or one that the person sees as significant, in a way that is based on their ‘own good’. Such decisions could include contracts involving a significant amounts of money, entry into a credit or mortgage arrangement, or major health care decisions.

Submissions to the Council stated that too often a paternalistic approach is taken by others in these circumstances, which substitute someone else’s idea of what is best for the person. As is discussed further in Part 9, pilots in the ACT with respect to the NDIS show that there are often limited opportunities for people with disabilities to exercise decision making abilities:

Many of those engaged in the project enjoyed very limited opportunity for self-determination with lives largely lived within the service sector and governed by the value and decisions of others, including families and care workers. ... For this group, support for decision making is also about creating cultural change that normalises active participation by people with disability in decision making, and by extension access to decision support, and builds the capacity of people who share their lives to enable participation in decision making on a day to day basis.

Similarly, submissions argue that the lack of legal recognition of supported decision making has been ‘a major barrier to decision making rights for people with disabilities’ and that ‘access to decision making is influenced by deeply embedded cultural values, reinforced by Guardianship laws, about the ‘inability’ of people with disabilities to be decision makers.’

It is common for people in general to use others for support in their decision making. These are usually trusted others in a person’s natural support network, such as friends and family. In the submissions to the Council, a person with a disability tells how he had used a Power of Attorney to secure the decision support of two relatives as his natural supports:

I liked that with the power of attorney I could choose who helped me with decisions. The people I chose listened to me carefully and explained things in a way I could understand. I had good experiences with that system.

164 NSW SDM Pilot Report 2015 – see note 62: page 12, but also pages 58, 66 and 69.
165 Submission 6 – Advocacy for Inclusion, page 15.
167 Submission 6 – Advocacy for Inclusion, page 32;
168 Submission 17 - ADACAS, page 1.
When other members of this person’s family obtained an order to place his affairs with the Public Trustee, he was less happy with arrangements, because he did not consider he was being given enough information about the consequences of that action. Under a supported decision making framework, this person would be expected to involve both about who was managing his affairs and, where he was able to be supported, to be directly engaged in decisions made in relation to himself and his affairs.\footnote{169}

7.2.4 Informal supports for decision making

A person who needs or wants support in making a particular decision or type of decision should be able to use supporters for decision making, on a voluntary and informal basis. When a person chooses such an informal support arrangement, the supporter must have the right to be present with the consent of the decision-maker, and the right to provide whatever support the person wants including declining their assistance. If a person decides that they do not wish to use the supporter for all or part of a decision, then the supporter is bound by this decision. The need to recognise the role of someone who provides decision making support in legislation is also out in the ALRC’s support guidelines, which state that such persons should be ‘acknowledged and respected – including family members, carers or other significant people chosen to provide support’.\footnote{170} Such recognition is likely to be necessary, so that people do not attempt to exclude a supporter on the basis, for example, of privacy.

The primary obligation on a supporter is to ensure that the person is able to discern and communicate their own will and preferences in the decision they make. Where there may be a conflict of interest between the decision-maker’s will and preferences and what the supporter believes to be the best decision, the supporter must not seek to influence the decision-maker towards the supporter’s will and preferences.

\begin{quote}
Priority must be placed on ensuring that informal decision making relationships are acknowledged and supported by legislation and legal processes. The wishes of the person with disability to have their chosen supports, informal or formal, involved in decisions should be enshrined in law.

Advocacy for Inclusion, Submission 6, page 32
\end{quote}

7.2.5 Formal supports for decision making

A person must be able to establish a formal decision making support arrangement, with one or more people, particularly when an assessment shows that a person’s decision making ability could be significantly improved through the provision of adequate support.

The ALRC notes that its approach provides ‘very strong support for legal models that reflect supported decision making norms and aspirations’, and that its Recommendations and Guidelines: ‘[r]eflect the Inquiry’s framing principles of dignity, autonomy, inclusion and participation’. The ALRC further notes that its Recommendations and Guidelines ‘are consistent with the general principles of the NDIS Act, that people with disability should be supported to exercise choice including in relation to taking reasonable risks; and receive reasonable and necessary supports, including early intervention supports’.

\footnote{169 Submission 1 – John Smith, pages 5, and 7: Mr Smith’s main criticisms related to the NSW Public Trustee. His experiences with the ACT Public Trustee and Guardian appeared to be better, but he believed the staff there were too busy.}

\footnote{170 ALRC Final Report – note 1: page 70, Recommendation 3-2(1)(c).}
There are many options for providing formal support for decision making, based on a person’s usual support networks, including:

- the person working with ‘circles of support’, where family, carers, friends and, if necessary, paid support workers may be involved in providing support eg under the existing PATH (Planning Alternative Tomorrows with Hope) program;¹⁷¹

- the person working with individual supporters chosen by the person for different decisions, for example a parent helps with financial decisions, and a sibling helps with personal decisions such as health;

- the person working with a small group of supporters in a trust-based relationship, without the presence of any service providers or professionals.

Arrangements need to be flexible to ensure they adapt to the needs of the person and their support network, for example, if a person decides that they can no longer be a supporter, or if the person decides a different person is appropriate to provide support in a specific part of their life, the formal process such as a written agreement or some other formalised process would need to be sufficiently flexible to provide for these kinds of changes to be made.

If a person does not have a natural support network they may need support through a community or statutory agency, which provides support on a professional basis. Most of the supported decision making pilots discussed in Part 9 identified social isolation and lack of a social support network as barriers to effective support for some people. In the NDIS pilots, resources were provided to help people with disabilities overcome social isolation and to build up natural support networks. Social isolation increases a person’s vulnerability significantly, and addressing this was an important safeguard.

A multi-layered approach to support is appropriate, first assisting the person to become decision-ready, and then building the person’s natural support network, so that they can either make their own decisions or derive support from a network. A support network is an important resource, a ‘framework for advancing people into good and valued lives’ through an intentional set of arrangements that authentically advance a person’s life chances towards citizenship in keeping with each person’s lifestyle choices.¹⁷²

After many years in the hands of the care apparatus, it may be difficult for an individual to express their own will. This is because as a patient, the individual felt that nothing they said mattered or that nobody listened. Different individuals need different amounts of time to express their own will.

Swedish National Board of Health and Welfare discussing the role of the PO

Because the complex circumstances of a person’s life can make the development of such natural support networks difficult or impossible, models have been developed in some countries to provide an on-going professional relationship of support. For example, in Sweden, the Personal Ombudsman (PO) program in Skåne provides cost effective decision making support and advocacy for people with severe mental health problems and psychosocial disabilities.¹⁷³ The PO program serves the most isolated people, those who have psychoses and who are homeless, who live isolated and barricaded, who are difficult to communicate with, or who are hostile to authority. POs operate

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¹⁷¹ Advocacy for Inclusion. 2013. – see note 154: at page 5. An example showing this model working can be seen at [https://www.youtube.com/watch?v=A3psS0qmmP0&list=PLF3907E73E8D8AB2B2&index=3](https://www.youtube.com/watch?v=A3psS0qmmP0&list=PLF3907E73E8D8AB2B2&index=3). PATH is a facilitated graphic planning process, which is designed to create a plan of action, to help someone achieve their aspirations, consistent with their values. The method was developed by Marsha Forest, Jack Pearpoint and John O’Brien in the early 1990s. Pearpoint J, O’Brien J and Forest M. PATH: Planning Alternative Tomorrows with Hope: A workbook for Planning Possible Positive Futures. 2001 Inclusion Press, Toronto.

¹⁷² Williams R. Model of Citizenhood Support. 2013 2nd Edition JFA Purple Orange, Unley (South Australia): see especially section 9, pages 46-62. This publication also describes how many of the ‘special’ services set up originally to help people with disabilities work negatively by separating them from opportunities to have a broader network of support. Williams is at the Julia Farr Association which worked in collaboration with the South Australian Office of the Public Advocate on the South Australian Supported Decision making Pilot.

independently from state institutions, and their work is directed by the concerns of the individual – the POs work with these isolated people and build up trust with them over time. The person then chooses if they want a PO to assist them. The PO program is driven by the UN Convention’s focus a person’s will, preferences and rights. The Swedish National Board of Health and Welfare describes the work of the PO in these terms:

- The client’s experienced needs and wishes are in focus, not the diagnosis and the treatment;
- The work is based on the client’s health and his/her potential, rather than on symptoms, problems and limitations;
- The client chooses the PO, not the other way round; and
- The client, and not the PO, sets the agenda and controls the process.

The legislative needs to reflect a flexible decision making process for people with impaired decision making ability, in recognition that their ability will vary over time and with the nature of decisions. In addition, the availability of support will also vary over time. The first and preferred step in the ACT Decision making Framework is to ensure the availability of a range of supports, where someone wants or needs assistance to exercise their decision making ability, based upon their will, preferences and rights.

Recommendation 6:

The Council recommends that the ACT Decision making Framework be based upon the provision of support for decision making, where someone wants or needs support to exercise their decision making ability. This support must be based upon the will, preferences and rights of someone whose decision making ability is impaired. Such support may include any actions which provide support for a decision-maker to exercise their decision making ability, including:

(a) reasonable accommodation; and
(b) the provision of various means of informal and formal support for decision making, with reviewable statutory guidelines about how such support can best be provided, without the prescription of a specific model.

7.2.6 Co-decision making agreements

When someone needs a high degree of support but can still make their own decisions, a further option is a co-decision making agreement. These exist in the Canadian provinces of Alberta and Saskatchewan, and in the Irish Republic. The options is supported by the Victorian Law Reform Commission (VLRC). A co-decision making agreement is a form of supported decision making which moves closer to representative decision making, but remains governed by the person’s will, preferences and rights. It is intended to ‘enable people with some impairment to their decision making ability to participate in decisions that affect their lives to the greatest possible extent without exposing them to potential harm’. Under a co-decision making agreement a person chooses a trusted other person to work with them to make their own decisions. Unlike supported decision making, a co-decision making arrangement requires joint decision making on the particular matters covered by the agreement. A legal document, for example, needs to be executed by both the co-decision-makers. The Irish Republic model requires that a co-decision maker must, if they cannot agree with the person, acquiesce to the person’s will, preferences and rights unless it is reasonably foreseeable that the serious harm will result to the decision-maker or another person. The VLRC model proposes that a co-decision making agreement can be

174 Further information can be obtained from the PO-Skåne website at: http://www.po-skane.org/ombudsman-for-psychiatric-patients-30.php and Swedish PO Booklet - see note168.
175 Swedish PO Booklet 2008 - see note168: see pages 16-17.
176 See Assisted Decision-Making (Capacity) Act 2015 (Irish Republic), Chapter 4. The Council received a comprehensive submission from the Centre for Disability Law and Policy, National University of Ireland - Galway, which provided additional information: see Submission 7.
177 VLRC Final Report 2012 - see note 88: see chapter 9.
178 VLRC Final Report 2012 - see note 88: paragraph 9.34, page 156.
179 See Assisted Decision making (Capacity) Act 2015 (Irish Republic), section 19(5).
created by an order of the Tribunal as part of the ‘least intrusive’ model of arrangements, or can be entered into without a Tribunal order but the agreement must be registered to be effective. It is consistent too with the existing Guardianship Act concept of interfering in the life of a protected person (including their lifestyle) to the smallest extent necessary (section 4(2)(d)).

The VLRC model proposes decision making principles that require the exercise of substitute decision making powers ‘in a manner that promotes the personal and social well-being of the represented person’ but with a definition of what this means that brings it close to a representative, rather than substitute ‘best interest’ decision. If a co-decision maker cannot agree with the person about the decision then the Tribunal must resolve the disagreement through mediation or by determining that the co-decision making order cannot function. Under VLRC recommendations the grounds for the original order is the inability for a person to make a specific decision without a co-decision-maker. The consequences of such a breakdown in the relationship for the person seems to be that the Tribunal would appoint someone else as a co-decision-maker or a substitute decision-maker, or the Tribunal would make its own decision on the outcome.

It seems to the Council that a co-decision making model is appropriate only when two people have a longstanding relationship of trust. Some models, including the one set out in the VLRC Report, specifically exclude statutory bodies such as the use of a Public Guardian as a co-decision-maker.

Where specific decisions could carry an unreasonable risk of substantial harm for a decision-maker acting alone, but where, with sufficient support, the person can still exercise their decision making ability, the Council proposes that a co-decision making option be available in place of supported decision making. Under this option, decisions are negotiated and agreed jointly by the decision-maker and the co-decision maker. The decision making is guided by the will, preferences and rights of the decision-maker. If the decision-maker and co-decision-maker are unable to agree, provision can be made for an appropriate independent person or agency to work with them, to support their relationship and assist in reaching a joint decision.

Recommendation 7:

The Council recommends the availability of co-decision making as a distinctive form of supported decision making where someone requires a higher level of support to exercise their decision making ability in relation to specific decisions, particularly those decisions which may involve risk of substantial harm to the decision-maker which risk cannot reasonably be ameliorated through risk reduction strategies.

7.3 When should representative decision making be allowed?

Representative decision making can become necessary as an alternative, where a person is not able to make a decision even with as much support as can be provided, and where ‘it is not practicable to determine the will and preferences of an individual’ for them. Some examples include people who are unconscious or in a permanent vegetative state, have the most profound intellectual disabilities or very advanced dementia. In other cases, people may have periods where they are not able to make a decision because they are experiencing profound delusions. In all these cases, the meaning of supported decision making would be pushed beyond its limits. As the Danish submission to the UN stated, in the absence of the alternative of representative decision making, it would:

run the risk of [the person] being exploited, neglected or even left to die. To assume that no one would ever require someone else to make a decision on their behalf would not only be flagrantly wrong but ultimately irresponsible.

Under the ALRC National Decision making Principles, representative decision making is seen as a last resort, only applicable when all forms of support have been exhausted. The Council believes this, too, should be the starting point under the new ACT decision making legislation. Where the person is assessed as needing a level of support
for decision making that is not practicable under existing arrangements and requires representative decision making at least in relation to some decisions, the UN Convention requires an even greater attention to adequate safeguards. The UN Convention states that:

Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.

Where representative decision making is required on either a short or long term basis, determining what the will and preferences of a person are or may be remains the first step. Given the complexities, a principles based approach to determining the will and preferences of the person is seen as a preferable one to attempts to prioritise one or more of a range of possible written documents over other ways of expressing will and preferences. In the case of representative decision making, there will always also need to be a consideration of the rights of the person who is unable to exercise their decision making ability, with any discernment of their will and preferences.

Under the proposed new arrangements, ACAT would have capacity to determine a range of possible orders to maximise the decision making power of the person, within a framework of will, preferences and rights. In determining this, if the person is able to express their views at all, ACAT should be required to comply with the person’s wishes about who should be their representative decision-maker, unless to do so, would breach one of the safeguards discussed in Section 8 below. In all circumstances, before an order to permit representative decision making is made by ACAT, the Tribunal must be satisfied that there is no other option possible without causing serious harm to the person. Any arrangement must be consistent with their human rights.

Finally, it is always important to remember that deciding not to make a decision is also a decision. Equally, just because the person’s decision does not agree with, professional advice or a doctor or a family member or that some might consider the decision unwise, does not mean that the person is not able to make such a decision. None of these circumstances give rise to grounds for invoking representative decision making.

### 7.3.1 The more limited role of representative decision making

In some cases, with all the support in the world, it will not be possible to support some decision-makers. At the most extreme end, where someone is unconscious and remains in a coma for a long period, any fictional construct of decision making ability is simply likely to lead to substitute decision making by stealth. In this case, the Council considers it is far better to recognise the existence of a representative decision making arrangement that is based, first on the known or discernible will and preferences of the person without decision making ability. Where the will and preferences of the person are unknown and unknowable, then the decision must be based on the person’s rights. The appointment of someone as a Representative decision maker should be by an order of ACAT, as a way of ensuring that there has been adequate evidence of prior supported decision making.

An elderly lady under guardianship and financial management wanted to install new curtains in her house. The Public Trustee considered it was in her best interests to sell her home and for her to move into assisted accommodation rather than spend money on a declining asset. The Public Trustee refused to release the money for the curtains.

*Information provided to LRAC in consultations*

The Council considers that if a person has entered a representative agreement to apply at a time when they are no longer able to make decisions, then the agreement should be honoured. This is the direction of the new Advance Consent Directions under the *Mental Health Act 2015*, discussed above at page 43. There will need to be adequate statutory safeguards for circumstances when acting on the representative agreement may cause serious harm to the person or a breach other human rights, and to ensure that the representative does not conflate the wishes of the person with the representatives own interests. While a person should be able to appoint someone as their Representative, in all cases, to ensure that it is being used as a last resort, the Council considers that the approval
of a representative and his or her powers in any case, should only be able to crystallise and become operational with the approval of ACAT be subject to the oversight of ACAT

Currently in the ACT, people may well be subject to financial management orders, whether or not they are subject to guardianship. This partly arises from the history of this area of law where it was intended to protect the financial position of the person, or in all likelihood, the assets of wealthy families, because of the cost of accessing such arrangements. Over time, this has become less expensive. It is also probably the area where paternalism has remained strongest. It is clear that the UN Convention intended that as much as possible, people with impaired decision making ability should be able to be provided with support to make most if not all of their financial decisions. Article 12(5) emphasises this:

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

The consequence of this is that current property management orders and the work of the Public Trustee underneath these, or within enduring powers of attorney vested in the Public Trustee, significant changes will need to occur. In many cases, this will involve working in a less coercive and more partnership manner with clients, because in all cases, the Public Trustee and the Tribunal will need to consider the will and preferences of the person first, and if these are not knowable, their human rights. For example, in the boxed story, the Public Trustee would be obliged to release the woman’s money to allow her to buy new curtains.

The ALRC model also provides for ‘will, preferences and rights’-based representative decision making as a last resort when neither supported or co-decision making are able to provide sufficient support for the person to exercise their own decision making ability. A representative decision-maker can be a person chosen by the decision-maker to represent them with appropriate safeguards, or, a person formally appointed by ACAT. In most cases, representatives would need to demonstrate that they have sought to support the decision-maker to participate in decision making to the greatest extent possible before they acted as the representative decision-maker and this would need to be recorded appropriately.

The Council makes the following recommendation:

**Recommendation 8:**

8.1 Where it is not possible to provide sufficient support for someone to exercise their decision making ability either as a supported or co-decision-maker, and a representative is appointed either by the person or by the ACT Civil and Administrative Tribunal, any decision made by a representative must be representative of the will and preferences of the person with impaired decision making ability, as well as being consistent with their rights.

8.2 Appointment to act as a formal representative decision-maker for another person shall be subject to application to the ACT Civil and Administrative Tribunal, to determine that options of supported and co-decision making have first been exhausted.

8.3 Where the need for a representative decision occurs in an emergency, there should be a temporary power for a person previously nominated by the person with impaired decision making ability to act as their representative, or alternatively a person who has authority under the existing Health Attorney provisions to make representative decisions for the person, based on their will, preferences and rights. Where the decision-maker does not recover their decision making ability in the short term, then approval must be sought for appointment as a representative decision-maker in accordance with the terms of 8.1 and 8.2 above.

7.4 Ascertaining will and preferences

7.4.1 Possible difficulties

The most obvious means of ascertaining someone’s will and preferences in relation to a specific decision is to ask them what their wishes are. While this sounds easy and obvious, there are significant complexities that can arise
in helping someone to work out what they want and what are their values and preferences. Even for those who have never been prevented from exercising their decision making ability, working out what they want to do in any particular set of circumstances can take some time and may involve, for example, talking through options to work out what feels right for them. Some people will take a long time and some may make quicker decisions – these are all individual variables, whether or not they have any impairment to their ability to make a decision.

[When Michael decided that he wanted to catch the bus to his day program, this wasn’t possible without the support of other people in his life. They would not agree, so] the decision was put on hold … and Michael worked on other decisions. … Michael’s desire to maintain good relationships with other people in his life is more highly valued than his desire for independence.

NSW SDM Pilot Report – Michael on page 67

People may have had limited decision making experience for a range of reasons. For example, they may live in a relationship where one person exercises decision making power over, or on behalf of the two. At one extreme, this may be a paternalistic but loving relationship, where one partner sees themselves as ‘looking after’ the other to genuinely help them. At the other end, it may be a relationship where there is an exploitative power dynamic, where a partner serves their own interests and does not regard the interests or wishes of the other. Sometimes, after someone’s decision making ability has been temporarily impaired for example through ill-health, and someone has been helping the person, the pattern of unilateral decision making may have arisen from necessity and then continued through habit. These complex relational dynamics can influence a person’s ideas about what is their will and preferences. This can be a special difficulty if they fear that they might offend someone who is important to them by making a specific decision or expressing a contrary views.

This is even more so, if that person provides them with support and the continuation of this support becomes contingent on the person deciding a specific way. This is most likely to happen, where a family member or service provider is afraid that the person will make a risky choice or one that imposes an additional burden on them. Where the consequences of a decision may be increased costs, worries or risks for someone else, without whose support the decision may not be able to be enacted, this can add significant complexities:

Whilst the UN Convention clearly sets out that people with disability should be afforded the right to make their own decisions, the reality of implementation in practice can be far more difficult, especially when a person’s decision may impact heavily on those around them.

The ability for people making decisions and people affected by those decisions to identify and discuss their interconnected interests is crucial for the effectiveness of the supported decision making process. However, this requires the development of additional skills and often the intervention of someone to work with both individuals involved to see what is possible.

A decision-maker also needs to understand what is important to them and what values they want their decisions to be based on. Part of the maturation and individuation of all children from their families as they grew, involves making these kinds of decisions. Where an adult has needed prolonged assistance from their family because of their disability, this process of growing into their adult self (separate from their parents) may have been suspended. Helping people to start to identify their own values and preferences can restart this process, but conflicts can arise when the values and preferences differ from their parents. This creates challenges for everyone, but is an important part of someone becoming their ‘own person’. For many adult people with disabilities, they may not have had this opportunity to develop at an earlier age.

When someone has not exercised their decision making power much or has limited experience in deciding what they want for whatever reason, the process of determining what they want can also feel overwhelming. Well-meaning

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186 There are a number of case studies in the NSW SDM Pilot Report 2015 (see note 62) that illustrate this, eg, Mandy’s iPad experience on page 73, Abdul’s experience with managing his anger safely on page 70; Michael and catching the bus on page 67.

people may ‘leap to their rescue’ with their own answer, or prompt in anticipation of what they expect the person should decide. Both of these actions, while well-meaning, can further discourage people from exercising and strengthening their decision making ability. Particularly where people have been providing support for someone through guardianship over a long period, changing their role in relation to the person to finding out what their will and preferences are can be both challenging and threatening. In a number of pilots, some substitute decision-makers were so uncomfortable that they refused to allow the person they were acting for to participate in the planned training for decision making.

Even statutory substitute decision-makers were sometimes resistant to these changing relationship dynamics. For example, in the NSW Pilot, people whose financial affairs were managed by the NSW Public Trustee showed least development in relation to their financial management skills over the period of the pilot. About 22% of people whose affairs were under management showed increased participation in financial decision making, while it was more than 50% across the whole sample. However this may have been because these people had higher levels of impaired decision making ability, it is not clear that this was the case. The NSW Public Trustee did not accept it had a role in training people to be better able to manage their money which may have also contributed to this result. Skills development for this kind of decision making is clearly important from the beginning, whether people are assisted by statutory or non-statutory supporters.

The process of helping someone to get to the point where they can look at their values, their resources and available information to determine their will and preferences in relation to a specific decision is called ‘decision readiness’. In all the Australian pilots, helping someone to get to this point has been a primary requirement for them to move to making their own decisions. This sometimes required a significant period of time and resources, particularly where people are inexperienced. For example, in its report Spectrums of Support, ADACAS describes the time necessary to develop decision readiness (including the primary phase of awareness building) took between 2-16 weeks for most people, with one person not achieving decision-readiness after 18 weeks.

Training for decision readiness could potentially be provided under the NDIS, which sets out principles ‘relating to the participation of people with disability’ in section 17A(3):

(3) The National Disability Insurance Scheme is to:

a. respect the interests of people with disability in exercising choice and control about matters that affect them; and
b. enable people with disability to make decisions that will affect their lives, to the extent of their capacity; and
c. support people with disability to participate in, and contribute to, social and economic life, to the extent of their ability.

The ALRC Final Report made recommendations in Chapter 5 to amend the NDIS legislation to ensure that its decision making activities became more closely compliant with the National Decision Making Framework as well as with the UN Convention. These recommendations specifically related to the NDIS nominee role, which is a form of substitute decision making not consistent with the Framework or UN Convention, and to building the NDIS’s capability for supported decision making in its interactions with Scheme participants. The ALRC noted the importance of training and guidance for all people involved in decision making in the NDIS – people with disability.

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188 This can happen in a supported decision making context. In the NSW SDM Report case-study of Michael discussed above, it is recorded that the facilitator decided that Michael prioritised good relationships over his desire for independence. Such a judgement may well limit the exploration of other options which might lead to his desire for independence and his family’s concern about the additional burden being better accommodated eg with a friend or professional aide to assist him, rather than imposing further on the family. See note 62: at page 67 in Michael’s box

189 See, eg, Submission 17 - ADACAS, page 5;

190 NSW SDM Pilot Report 2015 – see note 62: at page 70.


192 ACT Disability, Aged and Carer Advocacy Service (ADACAS) Spectrums of Support – A Report on a project Exploring Supported Decision Making for People with Disability in the ACT September 2013, ADACAS Canberra (Australia).

193 Disability Care Australia. My pathway, my choices, my goals – Information for participants. 2013 FAHCSIA: pages 8-10

194 National Disability Insurance Scheme Act 2013 (Cth). This provision appears in Chapter 3 dealing with participants and their plans. There are a range of other areas where the legislation sets out principles which could support this form of assistance eg section 31, dealing with principles relating to plans, especially (g), section 33, which discusses the participant’s statement of goals and aspirations and section 34, covering reasonable and necessary supports.

family, carers and services providers – ‘to ensure the effective operation of the supported decision making model.’

The NDIS operational guidelines relating to the role of a nominee recognises that, even where there is a nominee, the will and preferences of the person should be heard and their decision making skills enhanced wherever possible.

As is clear from this discussion, the ascertainment of someone’s will and preferences can itself be a complex process, that can take time, beginning with someone gaining a basic understanding of what they may want. It is anticipated that processes like the NDIS will have given some people with disabilities, whose experience with decision making may have been limited under prior arrangements, the opportunity to begin to think about their own values, goals and aspirations which can assist them in making decisions with support or on their own on an ongoing basis. Notwithstanding the complexities and subtleties involved in helping someone to truly identify their wishes and preferences, that determination is fundamental to empowering people to make their own decisions.

7.4.2 Advance decision making and directions

In some circumstances, people may experience periods during which their ability to make decisions about ‘their own good’ can be greatly impaired, while at other times they are not. This can arise when some has an episodic condition, like a mental illness, where someone experiences delirium; or when someone at a time they have decision making ability is making a plan for their future in anticipation that their decision making may become impaired. In these situations, it can be an advantage for someone to set down their will and preferences in a written document, when their decision making ability is not impaired or is less impaired. This is something which arises most commonly with health care decision making, but need not be limited to this area.

The concept of an enduring power of attorney is based on the theory, that a person who (in the old paradigm) has decision making ability, sets out their wishes for a time when they ‘lack capacity’ and appoints someone to make decisions on their behalf at that time. The theory is that the person giving the Power of Attorney is best placed to choose the person likely to decide as they would want to decide if they were able. In practice, experience shows that this can be more complex than theory envisages. People may make an enduring power of attorney a long period before it becomes ‘live’, that is, when they ‘lose capacity’, and their will and preferences, and circumstances may have changed. The person named may no longer be the appropriate person for a range of reasons: for example, their relationship may have changed, or the person may lack the current knowledge to stand in the person’s shoes or to act in their ‘best interests’. Because currently these documents are not registered, it may also be difficult to find the document, and to know if a document found is the most recent iteration. This was an issue discussed in a submission to the Council.

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197  National Disability Insurance Scheme. Operational Guideline – General Conduct – Supporting Participants’ Decision making (v 1.01) 19 December 2013, paragraph 9, which states that ‘Plan nominees have a duty to support the participant to make his or her own decisions wherever possible and to build the participant’s capacity for decision making.’

198  Submission 4 from various staff at Calvary Health Care.
7.4.3 Health care decision making

The importance of the legal requirement of consent in relation to health care decisions (unless there is a life or death emergency), has meant that this area has attracted a wide range of legislative procedures relating to forms of health care substitute decision making and ways of recording will and preferences. These include:

- creating a power to deal with a range of health care matters through an enduring power of attorney,\(^ {199}\)
- the creation of a health direction under the Health Directions Act,\(^ {200}\)
- the making of a guardianship order under the Guardianship Act, covering giving consent to a health procedure or treatment (Section 7(3)(e) (other than ‘prescribed medical procedures’ under section 70, consent for which can only be provided by ACAT),
- using the Health Attorney provisions of Part 2A of the Guardianship Act, that were introduced in 2008 and were discussed in section 3.1.5; and
- using advance agreements (under section 26), advance consent directions (under section 27) and nominated people under the Mental Health Act.

In addition to these statutory provisions, there is a separate administrative process through the Respecting Patient Choices Team in ACT Health, variously called an advanced care plan\(^ {201}\) or a statement of choices.\(^ {202}\) Neither of these instruments has statutory power, but they are intended ‘to inform your attorney and the doctors of your medical treatment wishes’.\(^ {203}\) While this is a useful initiative, and is supported by a central register in the Canberra Hospital, health care consumers have raised concerns that the electronic information is not available if someone is admitted to the Calvary Hospital.\(^ {204}\)

These provisions exist side by side with conflicting common law principles where consent is not required in a life or death emergencies (non-consensual intervention) or where doctors may choose not to provide or inform someone about specific kinds of care, if the doctor determines it is ‘medically futile’ (non-consensual non-intervention). In Council’s consultations, this later concern was raised in relation to care offered to people with disabilities. The example given related to a resident of a group home who was diagnosed with cancer. While the cancer was medically operable, the treating doctor refused to offer this treatment and said the man was to receive palliative care only ‘because of his poor quality of life’. When asked about this decision by group home staff, the doctor stated that living in a group home compelled his conclusion.\(^ {205}\)

What is most apparent when looking at current legal and administrative options is there confused status, both for doctors and patients. This is as true for those who are required to step into the shoes of, say an unconscious person, in relation to an often already stressful and unexpected health care decision. While different acts recognise the existence of other legislative provisions, their interaction is complex and not well understood and can often depend on the different sequence of documents which cannot readily be accessed or determined. The exact nature of someone’s substitute or representative decision making power is therefore likely to be unclear and the documents providing the legal basis for it may not be readily available.

Similarly, the limitations on what can be decided, or the ability to give consent and the principles on which these decisions are to be based are not always the same and often contradictory. The administrative requirements for each

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199 A health care matter is defined under section 12 of the Power of Attorney Act 2006. It excludes matters which are considered ‘special health care matters’ under section 37. While the power in relation to health matters is wide, an interested person can appeal to ACAT about the exercise of this power if it is believed that the attorney is not acting in the principal’s best interests (section 5). It is also subject to the principles outlined in Schedule 1 to the Act, which includes specific requirements under Principle 1.11.

200 The objectives of this Act are ‘to protect the rights of patients to refuse unwanted medical treatment’ and ‘to ensure the right of patients to receive relief from pain and suffering to the maximum extent that is reasonable in the circumstances’ (section 5).


204 Consultation meeting with ACT Health Care Consumers Association, 19 August 2015.

205 Dr Michelle Weise, speaker on Palliative Care and Intellectual Disability, at Disability Forum organised by Palliative Care Australia as part of their Palliative Care and Planning for your Future Program., Canberra 23 July 2015.
can be different. Part of the suggested reforms must be to introduce a health care decision making regime, which is straight forward, consistent, and predictable for both patients and doctors. By including health care decision making in the decision making legislation, many of the existing anomalies from the multiple options for health care decision making can be addressed and overcome.

Consumer and carer concerns voiced about the wider, potentially unpredicted negative effect of documenting their will and preferences at a single point in time are supported by research. Studies have looked at the general care of patients who document a not-for-resuscitation order. There is evidence that other more general life-sustaining treatments are sometimes withheld from such patients, and that as a consequence they are significantly more likely to die from non-resuscitation related reasons.206 Sometimes also, a treatment which may seem theoretically unacceptable when someone is fit and well at the time they are documenting their wishes, may be in fact, judged as more reasonable and acceptable when an illness or accident brings the decision into the present moment.

It is therefore important that, even if someone has expressed their will and preferences on health care matters at an earlier time, that this be seen as limited. The existence of such evidence should not be treated as definitive of their current will and preferences when circumstances have changed. Where possible, the person should be supported to re-make their decision in the current situation, rather than relying on past evidence.

The UN Convention and ALRC recommendations on decision making encompass the importance of provisions for someone being able to change their mind. This is reflected in discussion about determining someone’s will and preferences from a written document. In one of the submissions, positive reference is made to the operation of the Adults with Incapacity Act 2000 in Scotland. While the following description of its operation is not clear from the wording of the legislative principles set out in section 1 of that Act, the Law Society of Scotland describes the constructing of decisions as using a hierarchy where:

- present competent decisions (even as regards only some elements of a matter to be addressed) always take precedence, past competent decisions come next, and there is then a gradation through decisive present choices, significant present choices, present wishes and feelings, past wishes and feelings, information from persons closest to the adult, and so forth down a hierarchy, at the very bottom of which are the norms of the society of which the adult is a member.207

### 7.5 Implementing the ACT Decision making Framework

The Council believes that new Framework for decision making needs to ensure that it sets support pathway which must be explored and exhausted, before a representative decision-maker can be appointed or used. This includes reasonable accommodation, various forms of supported decision making and co-decision making. The legislation should allow a range of supported decision making models to develop and be tried, within the safeguards provided later, as the understanding of how best to support someone in any particular circumstance is still being explored. It is also likely that this will change over time, with different people and with different decisions, so the legislation should enable rather than prescribe at this stage.

What is also clear is that it is likely to take some time to build the capacity of decision-makers, supporters and representatives to understand and develop skills to operate under the new framework. One option that will provide a useful signpost for the community would be the use of an exposure draft for consultation prior to implementation. If the Government accepts in principle the need for the changed framework, then an exposure draft with a significant consultation period may allow better adjustment to the changes. In addition it allows the Government time to make appropriate arrangements and to set up an administration to handle the registration of documents where someone sets out their will and preferences, before there is any impairment of their decision making ability, as well as to ensure adequate safeguards are put in place.

The absence of statutory oversight under current guardianship legislation, including a mechanism for registration, was discussed in the Health Directorate’s submission,208 where the position of a guardian was compared to the obligations of the Chief psychiatrist, when making decisions affecting people under the Mental Health Act. It was...

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206 See for eg Shepardson LB. Youngner SJ. Speroff T. Rosenthal GE. Increased risk of death in patients with do-not-resuscitate orders. 1999 Medical Care, August, volume 37(8), pages 727-737; Sulmasy DP. Do patients die because they have DNR orders or do they have DNR orders because they are going to die? 1999 Medical Care, August, volume 37(8), pages 719-721


208 Submission 21- ACT Health.
noted that there were many more regulatory protections for people under that Act. Some of the areas of where a lack of oversight were of concern were:

- The lack of a register of guardians;
- The possibly unnecessarily wide powers of guardians to determine where someone lives and with whom;
- The lack of requirement of written decisions when a guardian makes important decisions for the protected person eg about where they will live;
- The sometimes time unlimited orders which can be unduly intrusive for many whose decision making capacity varies over time eg many mental health patients;
- The limitation on the guardian’s requirement to consult with carers and important others when a decision is made about the person – if the guardian decides such consultation is not in the person’s best interests they don’t have to consult;
- The lack of a requirement to report to ACAT is someone who no longer needs to be subject to substitute decision making.

The submission goes onto recommend a range of statutory protections that the Health Directorate considers to be necessary and appropriate for people with impaired decision making ability, to ensure that their human rights are protected.

The registration of all representative or supported decision making arrangements provides a means of enabling oversight of the arrangements by an appropriate oversight body, such as the Public Advocate or public trustee and guardian and for periodic review by ACAT as well as providing a means of ensuring that someone’s will and preferences are able to be accessed. This should commence as soon as possible, and initially include all operational guardianship orders and Enduring Powers of Attorney, sought to be exercised in the ACT, wherever made.

### 7.5.1 Determining and recording a person’s will and preferences

Respecting the will, preferences and rights of people who require support to exercise their decision making ability is a central feature of the new ACT Decision making Framework. Determining the will and preferences of a person with impaired decision making ability may require a new set of administrative processes. The determination will often be made through discussion and engagement between the decision-maker and their supporters, family, carers and service providers at the time of decision making. This is necessarily a staged deliberative process. Such a process of discussion and engagement is not possible for instance where a person is unconscious or otherwise unable to express their will and preferences. Some other process for determining the person’s will and preferences is then required.

There are a limited number of ways that a person can record their wishes and preferences under current legislation in the ACT. Existing provisions, particularly in relation to medical decision making, are complex and, at times, conflicting. There is no central administrative arrangement to record the will and preferences of a person for subsequent access when needed. A requirement to register any such expression of will and preferences could also allow an oversight or review body to have point-in-time evidence of the will, preferences and rights of the decision-maker.

**Recommendation 9:**

9.1 The new ACT Decision making Framework should provide the opportunity and a mechanism for people to formally record their will and preferences about specific issues, in a way that can be readily accessed when needed. Existing mechanisms such as advance care directions or consents and agreements under the Mental Health Act provide potential models. Extending such options to other areas of decision making should be explored and developed for affected persons to be able to formally record their will and preferences about specific issues.

9.2 Where existing Enduring Powers of Attorney are in operation, a transition period should be set to provide opportunity for such agreements to be registered or renewed so as to remain operative.

The first necessary step to ensure decision making arrangements can be safeguarded under the proposed ACT Decision making Framework is to know they exist. At the moment, there is no scrutiny of substitute decision making under the enduring power of attorney provisions of the Powers of Attorney Act, but the powers exercised may be as significant as those exercised under the Guardianship Act. In future, where someone wishes to appoint another
person as a supporter or a representative, a register will be required to ensure that these wishes are able to be known if and when needed.

**Recommendation 10:**

10.1 The Council proposes that in the transition period, all existing substitute decision making arrangements be brought under a common registration and monitoring regime, to facilitate the transition to the new ACT Decision making Framework.

10.2 Where a person wishes to nominate a supporter or representative for situations where they may need support for decision making in the future, administrative processes for the registration of all such agreements should be developed as part of the transition arrangements. Registration will facilitate the formal recognition of people’s will and preferences, and provide administrative capacity to monitor and review such arrangements to ensure the protection of the rights of decision-makers with impaired decision making ability.

### 7.5.2 Building community capacity for change

In addition to the need for legislation change, the paradigm shift set out in the recommendations above will require consequent cultural and procedural change. The new ACT Decision making Framework will affect many people, including existing guardians and managers, people subject to guardianship, carers and families, service providers, as well as the broader community. Significant community capacity building will be required to enable the effective implementation of these transitional changes in order to fully implement supported decision making.

The NDIS and its accompanying disability transition strategy has already commenced the required process of community capacity building. Many carers at the Council’s consultation meetings indicated that they were already moving to supporting their family member to make decisions. Learning from these experiences, the necessary building blocks for supported decision making need to be put in place alongside any legislative change.

Evaluation of the NSW supported decision making pilot defined supported decision making as ‘the process of assisting a person with disability to exercise their legal capacity to act on an equal basis with others’. This definition appropriately highlights the shift from the paternalism of the determination of a person’s best interests by someone else, to a rights-based approach where a person’s will and preferences, usually evidenced by their express wishes, are respected as defining the individual’s legal personhood and guiding their exercise of their own legal agency.

For people who are operating as substitute decision-makers under existing arrangements, using a ‘best interest’ test, the shift to giving effect to will, preferences and rights will be a challenging one. New insight, understanding and skills will be needed.

It is the Council’s view that significant community capacity building will be needed in order to properly enable the effective implementation of transitional changes to supported decision making which includes information dissemination, training and resources.

The first priority is to develop resources to provide explanatory information and to support educational programs to promote community-wide understanding of supported decision making. The recent evaluation of a supported decision making pilot in NSW emphasised the crucial importance of providing information in accessible formats.

Secondly, it is a priority to provide skills training for those who are decision-makers and guardians under current legislation. Such training should be developed for both on-line and face-to-face delivery, and be targeted to individuals or groups who will provide support.

Training is also required to assist community organisations and others to develop and provide training in supported decision making to people in guardianship arrangements. The NSW pilot showed that individualised training with supporters and the person they were supporting were considered both more helpful and effective than group training. There will need to be a period during which decision-makers can opt into the new arrangements once they completed appropriate training.

Thirdly, people who need and want decision making support will need appropriate administrative mechanisms to assist them in obtaining such support and in making supported decisions. In its submission to the Council,

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209 NSW SDM Pilot Report 2015 – see note 62: page 16
Advocacy for Inclusion recommends the establishment of a supported decision making hub, as a ‘central collection or repository for supported decision making information and resources, including independent explanation of the benefits and challenges of different decision making practices and customisable template agreements’. Advocacy for Inclusion proposes that the hub could provide training and independent explanatory information and include specialised staff who:

… would need to be experienced communicators and well-trained in presenting options in an unbiased unpressured style. The hub should not privilege or promote one particular style or method of supported decision making, but rather should encourage customisation and innovation to ensure people can receive decision making support in a way that suits their needs and preference.

Such a hub would provide a place for people to go for advice and information, and allow the development of specialised skills in accessibility to assist the making of reasonable adjustments to meet the needs of people requiring decision making support.

The Council considers that an adequate transition period is required, where elements of the legislative part of the Framework, are implemented, accompanied by appropriate education and community information. These changes are likely to require time and resources to develop and implement properly. Community capacity building which will be required to implement the new ACT Decision making Framework, include:

a. the development and provision of explanatory information and education programs to promote supported decision making skills and change decision making culture across the community;
b. support for relational changes necessary to allow greater decision making by those who are currently under a substituted decision making arrangement;
c. observation and learnings from pilot supported decision making processes;
d. development of ways of assessing the supports someone may need to exercise their decision making ability;
e. administrative mechanisms to help facilitate the making and implementation of supported decisions, including guidelines for the various roles in a supported decision making environment; and
f. development of appropriate registration processes, so that people can record their will and preferences and any formal arrangements they want to operate to support their decision making;
g. development and implementation of appropriate monitoring and oversight mechanisms, where these are necessary.

**Recommendation 11:**

The Council recommends that there be a transition period for implementation of the new ACT Decision making Framework in acknowledgement of the need for considerable community capacity building, the development and delivery of educational and information programs, and the necessary review of existing administrative arrangements to occur.

**7.6 A summary of key elements of the ACT Decision making Framework**

1. **Decision making ability**
   a. the decision making ability of all adults is presumed;
   b. the presumption of a person’s decision making ability is not rebutted by either a challenge to a person’s decision making ability, or the appointment of a supporter, co-decision-maker or representative decision-maker;

2. **Reasonable Accommodation**
   a. where someone’s decision making can be enhanced through reasonable accommodation for example by easy English explanations, through choosing a quiet place to enable them to think more easily, by providing communication assistance etc, this must be done;
3. **Supported decision making model**
   a. supported decision making requiring the determination of and compliance with the person’s will and preferences is the default decision making model;
   b. legislation will enable different models of supported decision making, rather than prescribe a single model, depending upon the needs and support resources available to the decision-makers, including co-decision making;
   c. representative decision making which occurs only when a person has no ability to make a supported decision or to co-decide, requires the determination of and compliance with the person’s will and preferences or, where these are not known, compliance with the person’s rights;

4. **Supporters and decision-makers**
   a. the roles of supporter, co-decision-maker and representative decision-maker be recognised and defined in legislation and coordinated with the NDIS to ensure a mutual recognition between the ACT and the NDIS processes of supported decision making;
   b. a supporter, co-decision-maker and representative decision-maker will support a person to make a decision that gives effect to the person’s will preferences and rights, limited only when compliance with their will and preferences is likely to lead to high risk of significant harm to themselves or others;

5. **Appointing a supporter or decision-maker**
   a. a person may choose to appoint another person as their supporter, co-decision-maker, and representative decision-maker either informally or by application ACAT;
   b. ACAT may, after a functional assessment of the person’s decision making ability appoint a supporter, co-decision-maker or representative decision-maker;
   c. an appointment by ACAT is for a specified decision or set of decisions, for the shortest time possible, with the least possible limitation on the person’s rights and interests, and subject to regular review by ACAT;
   d. any person may make an advanced directive appointing a supporter, co-decision-maker or representative decision-maker in future, to operate only when the person’s decision making ability becomes impaired, a functional assessment of the person’s decision making ability is carried out, and an order is made by ACAT to give effect to the advanced directive;
   e. a representative decision-maker will only make decisions that give effect to a person’s will and preferences as far as they can be ascertained, and otherwise that are consistent with the person’s rights;

6. **Enabling decision making**
   a. parties with an interest in a decision, defined by role or status in particular circumstances, have an obligation to make reasonable adjustments to support a person in their decision making;
   b. mechanisms which enable decision-makers to record their will and preferences for later consideration like advance directives should be able to be formally recorded so they are available if needed at any time.
PART 8: SAFEGUARDS

Overview of this Part

The UN Convention Article 12(4) requires that states put in place ‘appropriate and effective safeguards to prevent abuse’ related to the exercise of legal capacity, ‘in accordance with international human rights law’:

Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.

This Part describes some of the concerns, and corresponding safeguards, that need to be addressed when shifting to supported decision making.

8.1 Introduction

The framework of supported and representative decision making set out in the recommendations and detailed in Section 10 below is designed to replace all substitute decision making arrangements based in a ‘best interests’ paradigm. It has supported decision making at its centre, supplemented by representative decision making in situations where, even with the most support available, the person does not have the ability at that time to make decisions. The basis for any intervention is always to ensure that the will and preferences of the person are given effect, supplemented by their rights. This requires the establishment of appropriate safeguards as set out in Article 12(4) of the UN Convention set out above.

8.2 ALRC Guidelines

The ALRC Guidelines provide an instructive example of a simple set of safeguards:

Safeguards Guidelines (Recommendation 3-4)

(1) General

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

a. the least restrictive of the person’s human rights
b. subject to appeal, and
c. subject to regular, independent and impartial monitoring and review.

(2) Support in decision making

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

However, in relation to people with disabilities and decision making, there are a number of vulnerabilities that can arise and barriers to effective decision making which require consideration, many of which arise from the power imbalances that often exist in support relationships.
8.3 Vulnerabilities in a supported decision making context

8.3.1 Limited expectations and expressing will and preferences

The first necessary safeguard mentioned in submissions and the pilots arises in the context of the determination of a person’s will and preferences: a person’s ability to decide and express their will and preferences is open to inappropriate influence by those who are trying to help or protect the person. It may also be open to limitation, because the supporters, carers or family may have a limited views of the person’s abilities.

The family were thrilled. They never believed … this gentleman had this in him. I think they have taken a step aside and [are] realising the gentleman is capable of making some decisions. Whereas previously he has been coerced and molly-coddled and managed … so they’ve seen another side to him that they have absolutely celebrated.

_South Australian SDM Pilot Report, page 16_

The family or carers of a person with a disability may think or be advised to ‘not expect too much’ of the person. This can become self-fulfilling, particularly when the family or carer is trying to protect the person from experiencing ordinary life circumstances of success and failure. The NSW pilot evaluation found that the attitudes and actions of others could be a significant barrier to a person’s effective decision making:

In the main, the barriers to supported decision making were not intrinsic to the specific decision maker but to others around them, the general life circumstances of people with a disability such as social isolation (leading to difficulties with supporter recruitment), lack of power and familiarity with making decisions, low expectations by others, power imbalance and conflict of interest in relationships, and the length of time it takes for someone to be supported to become ‘decision-ready’.  

… I think we can understand him better because we’re listening. He hasn’t changed. In actual fact, the [training] probably didn’t change him, it changed us. You know, because institutions are mostly about what people need, but they’re generally not about what people want, and that’s the – it’s only a fine change, but it’s worth everything.

_South Australian SDM Pilot Report, page 8._

The NSW pilot evaluation noted the difficulty for some family members in moving to supported decision making:

Decision makers commonly nominated family members as their preferred supporter. Not all family members were willing to take on this role. The withdrawal of one participant from the pilot corresponded with the decision of her mother to decline to be involved in the pilot.

Trusted close relationships which an individual may have with a family member can be beneficial to the supported decision making process. Notwithstanding this, the pilot showed that in reality family members were not always a natural fit. Some family members did not wish to take on the role; in other situations, family members did not support the person’s desire to make more of their own decisions … Sometimes there was conflict of interest with family members as supporters.

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210 NSW SDM Pilot Report 2015 – see note 62: page 13
The NSW pilot evaluation reported that the fears of families and service providers can limit people in exercising their decision making ability:

The pilot showed a number of ways in which a person’s choices were limited. These included restrictive family attitudes and lack of interest in supported decision making, rhetoric around supporting the growing independence of family member with a disability but resistance in practice and a tendency (most notably among service providers) to prioritise duty of care over dignity of risk. In other situations, cultural norms in the family environment influenced decision outcomes. Supporters sometimes felt a protective need to stop decision makers from making decisions they considered risky.\(^{212}\)

The risk that a person’s ability to decide and express their will and preferences will be influenced by others who have low expectations of their ability is best addressed by transitional training, support and change strategies.

### 8.4 Managing risk

#### 8.4.1 Decision making and risk

The second safeguard recommended in submissions relates to the negative perception that supported decision making involves heightened risk. There are two aspects of risk that are relevant: the so-called ‘dignity of risk’, and the determination of potential harm from that risk.

There is, understandably, a risk-averse culture associated in the usual guardianship arrangements that engage in substitute decision making. This is described in the submission from Advocacy for Inclusion:

> Beyond the practice of formal substitute decision making through the provision of orders, a ‘culture of guardianship’ exists, brought about by long held protectionist beliefs about people with disabilities and their incapacity coupled with a focus on risk management.

Risk minimisation can exclude people with disabilities from participating in many life experiences. The fear of a person’s being hurt, making a poor decision, or suffering a loss has led families, carers and service providers to focus on minimising that risk, possibly at a cost to the person’s ability to experience, develop and enjoy a full life.

The desire to avoid risk can bring with it greater but more subtle risks. Risk-averse substitute decision making can affect the life choices and opportunities of people with disabilities, limiting the development of social networks and...
leading to social isolation. Social isolation is a risk factor in itself. In its submission Advocacy for Inclusion set out the risks for people with disabilities in the current system in this way:

People with disabilities are made vulnerable through the social and cultural environment, which places them in positions of powerlessness. They are devalued and disadvantaged by an inaccessible society, resulting in high rates of poverty, victimisation and social isolation, under employment and low levels of education. Guardianship compounds vulnerability, it does not negate it. Guardianship orders necessitate an imbalance of power, unequal access to legal assistance and uneven valuing of knowledge in both process and outcome. The perception that guardianship protects and cares for people with disabilities is unrealistic and must be challenged; as there are numerous and harrowing examples where this is not the case.

Noting that risk is viewed conservatively by support agencies, families and carers of people with disabilities, Advocacy for Inclusion says:

This means that people with disabilities, and particularly those under guardianship orders, are prevented from taking risks that people without disability may freely take.

8.4.2 The ‘dignity of risk’

Risk is inherent in all decision making, so the right to make a decision necessarily carries with it the risk of poor decision making; most people, especially when they are learning about making decisions, make some unwise, unfortunate or ‘bad’ decisions. People underestimate risks or do not pay adequate heed to them. This is part of the process of learning not only about decision making but also about exercising personal autonomy. As the ALRC said:

Supported decision making processes prioritise personal autonomy and recognise that individuals should be empowered with information to make decisions – even bad ones (acknowledging the dignity of risk).

Fear is implanted in us as a preservative from evil; but its duty, like that of other passions, is not to overbear reason. … When fear is discovered to be groundless, it is to be eradicated like other false opinions.


It is in this sense that all people are said to enjoy ‘the dignity of risk’; risk is integral to the dignity of exercising personal autonomy.

Both the ALRC Final Report and the NDIS Act encompass the concept of ‘dignity of risk’ in their discussion and principles. The ALRC notes in paragraph 2(d) of its Support Guidelines (‘A person’s decision making ability is to be assessed, not the outcome of the decision they want to make’) the prevalence of an outcomes-based approach in place of an approach that gives scope for ‘what is described as ‘the dignity of risk’ which is underpinned by the framing principle of autonomy.’ Despite submissions which warn against the idea that sometimes people should be able to make bad decisions, particularly in relation to financial matters, the ALRC states:

An important shift arises where the person involved has expressed will and preferences that are likely to be financially detrimental. While the [UN Convention] has referred to the need to protect people from

214 This was highlighted in Submission 6 - Advocacy for Inclusion, ‘The concept of vulnerability’, pages 20-22.
‘undue influence’, it has also said that protection must ‘respect the rights, will and preferences of the person, including the right to take risks and make mistakes’.\(^\text{219}\)

In the general principles of the NDIS Act, such ‘dignity of risk’ is clearly recognised:

s 4(4) People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports.

Supported decision making demands recognition and acceptance of the reality of risk. This means a shift in approach, from preventing risk to minimising risk. The risk of harm can be minimised in different ways. If, for example, there is a concern about a person returning to their own home from institutional care because they may not be able to manage the stove for cooking, then adjustments can be made to the environment, such as an induction cook top, a microwave oven, or ‘meals on wheels’. The effectiveness of these adjustments can be reinforced by a supporter discussing risks with the person, and ways of managing them. For example, if a person wants to travel on public transport unaccompanied, they may need skills development, with a training assistant, in the catching of buses or trains and timetabling, and assistance with ‘stranger danger’ awareness.

Supported decision making requires a supporter to explore options with the person, to identify outcomes of a decision that best align with the person’s will preference and rights while, at the same time, putting in place risk controls and harm minimisation strategies. This may mean trialling something which may or may not work. An example of this is given by the Swedish Personal Ombudsman:

After a stay in hospital, a client wanted to live in a flat of his own. Since this was the client’s wish, he was supported by the PO, while many other professional involved with the client advised against it, saying that it would not work out. This in fact turned out to be the case: the client eventually moved into housing with special support and was very happy there. Professionals in the social services and psychiatric services thought that this was an unnecessary failure, while the PO’s view was that the reason why the client was so happy in the special housing was that he had been given the chance to live in his own flat.\(^\text{220}\)

\section{8.4.3 Determining risk}

One consideration in determining appropriate risk safeguards is that people are usually not very good at determining the magnitude of a particular risk. Human beings are neurological wired to respond to threat, initially from an emotional response of fear and, possibly and later, in light of actual data on risk.\(^\text{221}\) A fear response can result in people attaching too great a risk to a rare event and ignoring the more common, frequent causes of harm. Often as well, the risks that people discuss are in fact concerns about their own liability if risks materialise; the concept of ‘duty of care’ is often raised by families, carers and service providers as a reason for their reluctance to respect the will and preferences of someone with a disability. The NSW Pilot showed, particularly among service providers, a prioritisation of duty of care over allowance of risk. The report also showed that this was an issue with supporters as well, when they felt ‘a protective need to stop decision makers from making decisions they considered too risky’.\(^\text{222}\)

It is unsurprising, therefore, that families, carers, service providers and regulators take a risk-averse approach to decision making for people with disabilities. The NSW Pilot report described the balance required:

While service providers may have a risk averse culture, some individuals might need access to specific training and skill development, which will enable them to safely undertake a proposed activity.

The report argues that once such training is completed, a further period of observation can avoid ‘the whole question of duty of care and dignity of risk’. However, the report recognises the issue of dignity of risk and duty of care as ‘a very real one’ which ‘needs to be identified, acknowledged and addressed’.\(^\text{223}\)

\begin{notes}
\item[220] Swedish PO Booklet – see note 168.
\item[223] NSW SDM Pilot Report 2015 – see note 62: pages 75-76.
\end{notes}
8.4.4 Unreasonable risk and substantial harm

It may happen that the only supported decision that is compliant with a person’s expressed will and preference involves a risk of substantial harm, such as death or injury, loss of home work or savings, or a violation of human rights.

In such cases where there is a concern that a decision by someone whose decision making ability is impaired would result in unreasonable and substantial risk of harm, the ACAT should be given power to intervene and determine whether the decision-makers wishes should be honoured or not, having regard to their will, preferences and rights.

This should not be a right exercisable in all cases of supported decision making arrangements or co-decision making arrangements. The right to review the will and preference of someone on the basis of unreasonable risk of substantial harm should be limited by the principle of autonomy exercised by ‘a competent, independent and impartial authority or judicial body’. This same limited review should also be the case with financial decisions.

8.5 Conflicts of interest, and undue influence

The third safeguard considered necessary in submissions relates to the need to acknowledge and prevent conflicts of interest and undue influence by supporters and representative decision-makers performing their roles. These issues can be complex. There may be a specific issue with people who are also in a service provision relationship with the person concerned, and in some cases with close family members, carers and friends. The use of monitors or of groups of people to act as supporters provides a safeguard and can reduce the potential for inadvertent exercises of undue influence or conflicts of interest. In all cases, there will be a need for training in the expectations of someone in these roles, to ensure that the change in the underlying paradigm as a result of these reforms becomes the lived experience of decision-makers, their family, carers and service providers. In some cases, there may need to be a paid person to fulfil this role.

8.6 Resolving conflicting rights

The fourth set of safeguards recommended in submissions relates to resolving conflicting rights. In supported decision making, where the rights of the person are paramount, there will be occasions when these rights compete with those of others. For example, a person’s right to make their own life choices may be at odds with their (and others’) right to life if their decision involves risk or danger.

Although there is a standard approach to assessing when a limitation on a right is justified, it may be necessary on each occasion to decide whether action in pursuit of one right is a justifiable limit on the enjoyment of another right. Over time, as the same issues recur, the same decision can be anticipated, but it remains the case that the question must always be asked and answered: is the limitation of a right justified?

Such a constraint on the limitation of rights is implicit in the ALRC Safeguards Guidelines which require that interventions for persons who require decision making support are ‘the least restrictive of the person’s human rights’, and that the appointment of a representative decision-maker should be ‘limited in scope, proportionate, and apply for the shortest time possible’.

8.7 Ensuring oversight and review

The Council has been consistently aware of the need to provide a proper balance between promoting the rights of people with impaired decision making ability and the need to consider the risks that may arise, particularly where the person may suffer great harm without some protection being in place. At the same time, the Council is clear that risk is an appropriate element in all decision making and that people with impaired decision making, like everyone else, may sometimes make unwise decisions. The Council is also aware that it is important that supported decision making results in decisions that are consistent with the will, preferences and rights and are not used as a way of exercising undue influence on the decision-maker, in exercising their decision making ability with support. The Council considers there needs to be a monitoring and review mechanism to provide a light touch but effective set of safeguards.

224 UN Convention – see note 66: Article 12(4).
225 UN Convention – see note 66: Article 12(5)
The implementation of a new paradigm in relation to decision making may involve difficulties for some people in making the transition. As noted above, there will be a significant need for capacity building for both decision-makers, supporters, family, carers and service providers. During the transition period, there must be a focus on skills development and education to encourage a willingness to “try out” new ways of behaving until affected people feel comfortable in the new paradigm. To ensure that decision-makers who need support are able to use their own decision making ability, there will need to be scope to seek appropriate advice. At times, intervention may be required to ensure the will, preferences and rights of the person requiring decision making support are being respected and acted upon. Such oversight and review functions should lie with the Human Rights Commission and/or ACAT.

**Recommendation 12:**

12.1 Where a person who needs support to exercise their decision making ability considers that their will, preferences and rights are not being respected, a right to seek advice and intervention from the Human Rights Commission or where necessary, review by the ACT Civil and Administrative Tribunal should be established. Grounds for intervention or review would include breaches of the Guidance Principles in Recommendation 10 including for example:

(a) a supporter’s unreasonably limited expectations of a decision-maker's ability, resulting in the decision-maker having little or no opportunity to exercise their decision making ability to make their own choices;

(b) unreasonable curtailment of risk;

(c) conflicts of interest;

(d) undue influence;

(e) competing rights between the supported decision-maker and their supporters;

(f) breach of a prescribed standard, resulting in a decision-maker being unable to exercise their decision making ability; and

(f) decision-supporter overreach.

**8.8 Principles and Guidelines for supporters, representatives and others**

There were also submissions suggesting the inclusion of a set of principles for decision-supporters that could act as an additional pre-emptive safeguard by providing a source of clear guidance. The submission from ACT Disability, Aged and Carer Advocacy Service (ADACAS) provided a useful example:

**ADACAS Principles for Decision Supporters**

Every person and every decision will need their own supports. ADACAS has developed these principles to provide a framework for giving decision support. They protect decision supporters as well as decision makers. To be a decision supporter you must be able to agree to work to these principles.

1. **Every Person has the right to decide**

   You are born with this right. When you support a person to decide, you are supporting them to use this right, as far as they are able.

2. **The right to decide can be exercised with support**

   Regardless of their decision making ability, all people can be supported to be involved in the decisions that affect them. The focus is on support not capacity.

3. **Equality**

   Decision support is about enabling a person with a disability to approach decision making with the same expectations, freedoms and responsibilities as those who do not have a disability.
4. Respect the decision maker and their decision

To support a decision you must be able to respect the values, experiences and goals of the decision maker. You must do this even when you do not share them, or agree with the decision they are making.

5. Give only as much support as is needed

You must only give as much support as is needed so that the decision maker remains active and engaged in their decision. Recognise that different decisions will need different supports and levels of support may change over time.

6. Everyone has something to learn

Supported decision making is not disability specific. Everyone has as role. Everyone has something to learn. Decision making is a skill that you learn. So is supporting a decision.

7. The decision being made belongs to the decision maker

The decision maker is free to choose the decisions they want to make and who will support them. They are free to change their mind, learn from experience, be ambitious or creative, take a risk and make decisions that others don’t agree with. Supporters must be able to recognise that the decision belongs to the decision maker. They are supporting the decision, not the outcome.

8. Be mindful of your vested interests

Everyone has vested interests. You must be able to recognise your own vested interest in the decision being made, and in the life of the decision maker, and then consider if you can truly support the decision according to these principles.

9. The decision support relationship must be built on trust

If you cannot give support according to these principles then the decision support role is not the right one for you. The biggest difference you can make to the decision maker is helping them identify a person who can give support according to these principles.

The new ACT Decision making Framework requires supporters, representatives and others who have been acting under the ‘best interests’ substitute decision making paradigm to operate very differently in supported decision making. This will involve a significant shift in the power dynamic within close and sometimes complex relationships. To facilitate this, statutory non-statutory guidance which is consistent with the ‘will, rights and preferences’ supported decision making paradigm will need to be developed and adopted during the transition period. The development of this guidance will need to take account of the results of supported decision making pilots conducted around Australia, as well as as changes to decision making as a consequence of the implementation of the NDIS.

**Recommendation 13:**

The proposed ACT Decision making Framework should include guidance materials (both directive and informative) for supporters, representatives and others to guide their behaviour appropriately in supporting a person to exercise their decision making ability.
PART 9: CURRENT TRENDS IN GUARDIANSHIP LAW POLICY AND PRACTICE

Overview of this Part

The implications of the UN Convention for guardianship arrangements have been the subject of research and experimentation. This Part describes what has been done in the area, particularly in the conduct of projects that pilot supported decision making models.

9.1 The ALRC inquiry

As discussed earlier, the ALRC received Terms of Reference to ‘undertake a review of equal recognition before the law and legal capacity for people with disability’ in July 2013, and its Final Report on that reference was tabled on 24 November 2014, just as the Council was beginning its inquiry into the effect of the UN Convention on the Guardianship Act.

The scope of the ALRC reference covered ‘all relevant Commonwealth laws and legal frameworks that either directly or indirectly impact on the recognition of people with disability before the law and their exercise of legal capacity on an equal basis with others’. It extended to access to justice and legal assistance programs, administrative law, aged care, anti-discrimination law, board participation, competition and consumer law, contracts, disability services and supports, electoral matters, employment, federal offences, financial services including insurance, giving evidence, holding public office, identification documents, jury service, marriage, partnerships, parenthood and family law, medical treatment, privacy law, restrictive practices, social security, superannuation, and supported and substitute decision making.

Relevantly to the Council’s inquiry, the ALRC considered “how maximising individual autonomy and independence could be modelled in Commonwealth laws and legal frameworks”. We set out here those parts of the ALRC Final Report that relate to the Council’s inquiry.

The ALRC’s ‘five framing principles’ of dignity, equality, autonomy, inclusion and participation and accountability and their National Decision making Principles and Guidelines are discussed in Section 7 below and the basic information will not be repeated here. The Council believes them to provide a very useful basis for reform of Guardianship and other substitute decision making arrangements in the ACT.

The ALRC Final Report provides a detailed analysis of the interaction between the Australian Government and the UN on these important issues, and attempts in its recommendations to meet these concerns. In particular, the ALRC notes that the UN Committee does not permit a ‘best interests’ approach to substitute decision making. The ALRC considers that its recommendations – for supported decision making wherever possible, and for ‘representative decision making’ where someone’s decision making ability is so impaired that it was not proper to characterise a decision as theirs – are likely to meet the concerns of the UN Committee.

The ALRC Final Report comments particularly on laws (similar to those in the ACT) which refer to both ‘will and preferences’ and ‘best interests’. The ALRC discusses the conceptual confusion in these laws and the need for greater clarity about the role and meaning of the person’s will and preferences:

Conceptual confusion is also exacerbated when models use ‘best interests’ language but expressed in terms of giving priority to the person’s wishes and preferences. Given the tensions around the usage and understanding about substitute decision making – and the blurring between ‘substitute judgment’

and ‘substitute decision making’ – the ALRC considers that it might be preferable to move away from this language altogether.\textsuperscript{231}

The ALRC proposes the terms ‘supporter’ and ‘representative’, to emphasise that when supported decision making is not possible and substitution is necessary, the decision is still a representative ‘substituted judgment’ based on what the person wants or would have wanted or, if this cannot be determined, based on their human rights.\textsuperscript{232}

Under its recommendations in Chapter 4, the ALRC sets out how supported decision making would work in Commonwealth laws, including a requirement that the terms ‘supporter’ and ‘representative’ are included and that all Acts concerned with decision making reflect the National Decision Making Principles. There are also a number of additional provisions relating to the appointment and roles of both supporters and representatives, and about the alteration of these arrangements.

There are numerous areas of Commonwealth law where the issue of decision making ability arises, eg under ‘fitness to plead’ arrangements in the Crimes Act 1914 (Cth), under mental incapacity provisions in the Corporations Act 2001 and the Commonwealth Electoral Act 1918, and for consent to marry in the Marriage Act 1961. The ALRC proposes that the various tests of incapacity in this legislation be replaced by a test of a person’s ability to understand the nature and effect of a decision, and of the person’s ability to make a decision with support. The ALRC proposes a framework for assessing this ability:

\begin{itemize}
\item the person must be able to understand the information relevant to the relevant decision
\item the person must be able to retain the information for a sufficient period to make the relevant decision
\item the person must be able to use or weight the information as part of the process of making the relevant decision, and
\item the person must be able to communicate their decision in some way.
\end{itemize}

The ALRC recommended that State and Territory government review their laws and legal frameworks concerning individual decision making to ensure consistency between this framework, interaction with any supporter and representative arrangements provided under Commonwealth law (for example the NDIS), consistency between jurisdictions in terminology, provisions for maximising cross-jurisdictional recognition of arrangements, and adoption of mechanisms for national data collection.\textsuperscript{233} This is the path adopted by the Council in this inquiry – we used the foundations of the ALRC Final Report as the basis for our consultation and policy considerations, and have sought to be consistent with all of its recommendation including the National Decision making Principles and revised language.

\subsection*{9.2 National Supported Decision Making Framework}

The Australian Supported Decision Making Network brings together practical expertise on implementing supported decision making in Australia. Established in 2012, it has more than 100 members including people with disabilities and their families, and non-government and Government Agencies.

In April 2016, the Network published its Discussion Paper Calling for development of a National Supported Decision Making Framework which proposes the development of a National Framework as a means of engaging ‘policy makers, governments and other stakeholders in articulating a common vision for implementation of the [ALRC’s] National Decision Making Principles’.

\begin{itemize}
\item\textsuperscript{231} ALRC Final Report 2014 – see note 1: paragraph 2.72: at page 52.
\item\textsuperscript{232} ALRC Final Report 2014 – see note 1: paragraph 3.60, at page 60. This text clarifies further the intention to move away from a ‘best interests’ paradigm.
\item\textsuperscript{233} ALRC Final Report 2014 – see note 1: Recommendation 10-1
\end{itemize}
The discussion paper sets out the wide-ranging potential uses and benefits of supported decision making for people with impaired decision making:

- an alternative or an adjunct to guardianship
- enable people to retain their legal capacity through being an alternative to enduring documents or powers of attorney as well as enable people to make arrangements of their choosing to be implemented in the future if requires (advance directives);
- a means by which a person can exercise their decision making ability with support; such as in mental health care and treatment decisions where it can be an alternative to involuntary treatment orders;
- enable people to access a range of other rights including having equal access to healthcare; by being active participants in health care decisions;
- support access housing, legal, financial, telecommunications and other services;
- extend into people’s personal lives to make decisions around who they live with, their supports and services, meaningful employment and the activities they participate in; and
- enable people to have self-determined relationships, to enjoy a right to privacy and dignity, and the fulfilment of other social and cultural rights. (pages 4-5)

The discussion paper describes steps in Supported Decision Making that have emerged from practice across the community, noting that the supports needed and used will vary over time and with the particular decision. These steps include:

- building capability to recognise the role of decision making, the right to equality and self-determination
- learning about decision making
- recognising and expressing a decision
- identifying and establishing support
- exploring a decision
- accessing information to inform a decision
- advocating for the decision
- fulfilling the decision
- ongoing support for another decision.

The discussion paper sets out the range of stakeholders that need to be engaged in the development of the Framework. It acknowledges the need for the Framework to cover a spectrum of responses given the often changing levels of support that a person may require. Consistent with the recommendations of the Council, the discussion paper recommends that legislation and regulatory and policy frameworks embody the ALRC’s National Decision making Principles.

The discussion paper elaborates on the need for appropriate safeguards and an appropriate balance of risk in supported decision making. This balance is expressed as ‘maximising the person’s decision making potential and autonomy while keeping risk to an acceptable level’. The discussion on risk includes a consideration of the dangers associated with over-protection, and the benefits associated with a less protective approach to decision making. It proposes legislative adoption of supported decision making in a way which ensures that it achieves the same traction claimed for ‘duty of care’ obligations. Claims of duty of care obligations have been used to prevent someone with impaired decision making from exercising their ability with support, leading instead to someone acting as a substitute decision maker.

The discussion paper also calls for the establishment of consistent language, capacity building, and necessary funding. It advocates the reallocation of resources from substitute decision making to supported decision making, and proposes innovative approaches to ensure a sustainable shift to supported decision making including co-design with stakeholders and community capacity building.

The discussion paper notes the need for evaluation of models, not only to ensure UN Convention compliance but also to build an evidence base about what works, and works best in particular circumstances.

The discussion paper also proposes a set of arrangements to create the Framework – involving a national supported decision making conference involving all stakeholders, the establishment of a national advisory committee on supported decision making with responsibility with driving the agenda (including the creation of the Framework) and
increasing the focus on experiential forms of research, that recognise and use the expertise of people with disability, their families, carers, and supporters and the community sector.

9.3 Supported Decision making Pilot Projects in Australian jurisdictions

9.3.1 South Australia: 2010-12 Office of the Public Advocate Pilot

Introduction

The Office of the Public Advocate of South Australia (OPASA) conducted a Supported Decision making (SDM) pilot project between December 2010 and October 2012. The project was non-statutory, and in some circumstances operated alongside existing Guardianship Orders or Administration Orders.

Methodology

The project featured the participant – that is, the person to receive decision making support – one or more of their supporters, and a monitor. Participants chose to participate in the pilot and identified which decisions or types of decisions they wanted support to make. They identified who they wanted as a supporter or supporters, and understood and accepted that the relevant decisions would be their own, not that of their supporter or supporters. Participants were able to leave the arrangement at any time.

When possible, the participants drew their ‘supporters’ from existing networks of trusted family and friends. The project coordinator assumed the role for some of the participants who could not find suitable supporters or where a supporter withdrew. Supporters were required to take the role willingly and have knowledge of the participant’s personal goals.

A monitor for each participant was appointed with oversight of their involvement in the process, and was a point of reference if problems arose.

Profile of participants

The project involved 26 participants who agreed to a Supported Decision Making Agreement.

Recruitment criteria limited participants to people with an intellectual disability, acquired brain injury, or neurological disease. Phase 1 of the project did not include anybody with a mental illness. The organising committee excluded from eligibility people with dementia, or mental illness as a primary diagnosis. In addition, participants who had been assessed as experiencing abuse or neglect were excluded as were those who had been involved in ‘significant conflict’ with family and friends.

Decision making

Central to the project was a ‘Supported Decision Making Agreement’, setting out details of the participant and supporter, and the areas of decision making which the participant wanted to have covered.

The types of decisions or areas of decision making that the participant could select to be covered by the project were principally those relating to accommodation, lifestyle and health decisions, consistently with what could be included in orders under the Guardianship and Administration Act 1993 (SA). The Act provides for guardianship orders to be made for people with mental incapacity, which meant such persons were unable to look after their own health, safety or welfare or to manage their own affairs, and orders could include any or all decisions about health, safety and welfare. Differently from guardianship orders, administration orders could be made for the management


of a person’s affairs, including property related financial matters and various legal matters. The project’s organising committee excluded financial decisions of a type that would be covered by administration orders.\footnote{236}

**Safeguards**

The primary safeguard for the project was that the participant and supporter made the decision as part of the Supported Decision Making Agreement, in the context of a trusting relationship. Further safeguards derived from the roles of project coordinator and monitor, and the provision of information to participants about the Office of the Public Advocate’s Complaints Policy.

**Outcomes**

The evaluation found (pp 4-5):

- The Supported Decision Making project has demonstrated that there were specific benefits to most of the participants. These were seen in their increased confidence in themselves and in their decision making. There was evidence of improvement in decision making skills. Participants described the growth in their support networks. Many reported that they felt more in control of their lives. Participants gave evidence that they had increased their engagement with the community, either through expanding their options or through making decisions that changed their circumstances.

- ... The evaluation gives evidence that Supported Decision Making was both a companion process and viable alternative to substitute decision making for participants who were initially on Guardianship Orders.

**Issue: Guardianship**

An issue was that some guardians expressed ambivalence about the concept of supported decision making, and confusion about overlap. In particular, they expressed concerns about whether the supported decision making process might conflict with their legal obligations and responsibilities in relation to guardianship. This suggests the need for careful consideration of legal obligations and responsibilities on guardians when a formal guardianship regime operates alongside a supported decision making scheme.

The evaluation commented (pp 45-46):

> Should Supported Decision Making continue to be seen as a viable alternative to Guardianship, the experience of the project points to the need for a considered process, within the processes and structures of guardianship, to identify potential users of Supported Decision Making, and the need to clarify, at a public and formal level, the boundaries and intersections between Supported Decision Making and guardianship.

> The project did demonstrate that, where criteria are clear and the relationship between Supported Decision Making and guardianship is delineated, Supported Decision Making can be a viable alternative to Guardianship. It showed that Supported Decision Making can build capacity to the extent that some existing Guardianship Orders could be revoked.

**Issue: supporters**

An issue was that more socially isolated participants could not find a supporter among friends or family, and the project coordinator had to take on that role. This suggests that access to supporters may be an issue in future schemes.

In relation to the availability of supporters, Oxenham notes that service providers who take on the role need to consider any conflict of interest issues, and that volunteers who take on the role need to consider the implications of the absence of a pre-existing relationship with the supported person.\footnote{237}

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**Issue: the monitor**

An issue was that while the concept of the monitor as separate from supporter is intended to separate responsibilities, the de facto ‘monitor’ for everyone in the pilot was more often the support meetings that took place between the project coordinator and senior staff of the Office of the Public Advocate.

In recruiting participants for the project, it was discovered that it would be too difficult for each supported decision-maker to find somebody they could appoint as a ‘monitor’ from their networks. There was already considerable difficulty finding a ‘supporter’, and that was where effort was best expended. There were just not enough people in the supported decision-makers’ lives from whom a ‘monitor’ might be drawn.\(^\text{238}\)

It was considered that the project structure itself provided a sufficient ‘safeguard’, such that the monitor ‘safeguard’ was not necessary.\(^\text{239}\)

The evaluation noted (p 53) that ‘[t]he role of monitor in the service model will need to be re-assessed for its applicability in processes which, when in the community, will not operate of necessity within a human research, ethical framework.’

**Proposals for legislative reform**

In 2013 the South Australian Public Advocate, in its advisory role about the operation of the South Australian Guardianship Act, recommended two legislative amendments concerning supported decision making: amending the key principles in the Guardianship and Administration Act 1993 (SA) to require supported decision making, and including new sections in that legislation to give statutory recognition to supported decision making arrangements.\(^\text{240}\)

Neither of these suggested amendments have been enacted.

The Public Advocate also discussed the importance of broader changes to incorporate supported decision making in the new Disability Services environment coming to South Australia with the NDIS.\(^\text{241}\) In 2013 this broader context was addressed though two amending Acts which adopted a supported decision making approach: the Disability Services (Rights, Protection and Inclusion) Amendment Act 2013 (SA), which requires disability services providers to engage in supported decision making in their work with people with disabilities, and the Advance Care Directives Act 2013 (SA), which in s10(d) provides ‘a person must be allowed to make their own decisions about their health care, residential and accommodation arrangements and personal affairs to the extent that they are able, and be supported to enable them to make such decisions for as long as they can’.

**9.3.2 South Australia: 2013-15 HCSCC Pilot**

**Introduction**

Following the 2010-2102 pilot, the Office of the South Australian Health & Community Services Complaints Commissioner (HCSCC) commenced a two stage project. This started with a pilot stage from October 2013 to May 2014 (the HCSCC Pilot) followed by a second project stage ran from August 2014 to May 2015 (the HCSCC Project). An independent evaluation for the Pilot was released in August 2014, and an independent evaluation of the Project was released in late 2015.\(^\text{242}\)
Methodology

The HCSCC described the model as being centred on the decision-maker, and one or more supporters. The pilot trained, mentored and coached nine workers – known as ‘facilitators’ – from seven different Government and non-Government disability services to act as project coordinators.

The pilot used voluntary supporters drawn from the participants’ existing circles of family and friends. The main focus of the project was building capacity in all parties, the participant, the supporters, and the facilitators whose job it is to work with both the participant and the supporter to establish supported decision making skills.

The facilitators recruited participants, supported participants in choosing their ‘supporters’, recruited supporters if necessary, facilitated meetings, provided appropriate follow-up and, coached, supporters to develop their ability to support the participant. The pilot emphasised an intention to ensure that participants learned and practised with their supporters ‘expressed wish decision making’ rather than ‘best interests’ decision making.

Profile of participants

The HCSCC Pilot recruited 11 participants and nine facilitators. The HCSCC stated:

The decision makers are people with complex needs including physical and intellectual disabilities, with some being non-verbal. Some live in institutional settings and/or are dependent on disability services for most of their needs.

Outcomes

In assessing the pilot, the HCSCC found that a short intervention, of three or four months, was enough to produce material change in the lives of participants. Their support needs eased and their opportunities for independence expanded, irrespective of their financial or service provision situation.

The reported outcomes were positive:

In most if not all cases, significant mental health and wellbeing outcomes were also identified. Most common were increased confidence, self-esteem and pride. However, one person was reported to be sleeping better and others as being happier, more goal oriented and more focussed.

Five of them made significant life changes, while the other three saw outcomes described by facilitators as ‘small’, or as not yet achieved due to delays. Yet, the report says: Even ‘for these decision-makers, changes in relation to mood, self-esteem and focus were noted, and impacts on the understanding of other people were identified’.

Issue: Guardianship

An issue was that the program has explicitly excluded people under concurrent guardianship orders. The one participant admitted to the program who was under guardianship made some of the more significant gains from the program. Some respondents to the evaluation argued that concurrent guardianship should not be a barrier to making at least some supported decisions.

Issue: Greater administrative flexibility and management training

An issue was the need for greater administrative flexibility, such as options other than team meetings, and for variable individualised training for facilitators, managers of Agencies, supporters and participants. It was found to be sometimes difficult to get people together for meetings, and there were occasions when failures to follow-up led to longer delays.

Issue: Limited expectations and conflicts of interest

An issue was that both service providers and supporters had low expectation levels for participant decision making ability. Often the long history of substitute decision making coloured this attitude. As well, when the facilitator or supporter needed to support someone in a decision, conflicts of interest often arose, and this was not always easy to prevent or address, suggesting the need for specific skills in supporters and adequate safeguards.
9.3.3 South Australia: 2013-15 HCSCC Project

Methodology

The project methodology was similar to that for the pilot, with reduced participating agencies and an MOU adopted to clarify roles and expectations of all parties. Additionally:

- the role of agency liaison was introduced to act as in-house support for trainee facilitators and back-up if the trainee left or took extended leave
- the time available for trainee facilitator was increased to one day a week
- the introductory training was extended from 4 to 6 days with an increase on practical skills needed
- a structured de-briefing process was introduced, and
- the restriction on entry of people under guardianship was removed.

Profile of participants

Ten trainee facilitators – five from each of two disability service sector organisations – along with their work supervisors, were trained in supported decision making processes. In addition, two facilitators who had participated in the initial training organised by the project coordinator, were appointed to the new Agency Liaison position. Ten decision-makers were recruited, which reduced to 8.

Outcomes

The supported decision making model used was seen as effective in the following circumstances:

- where there is a facilitator and back-up facilitator
- where facilitators are supported in practical and emotional terms by the program and their agency
- where decision makers have:
  - cognitive ability to make decisions
  - a mode of communication
  - adequate mental health
  - an interest in making choices
  - time to commit to learning the skills, and
  - at least one supporter who could be identified and wanted to be involved.

Positive outcomes were reported for six of the eight decision-makers – one had withdrawn before completion and one had mixed outcomes. These positive outcomes covered a wide range of benefits:

Positive outcomes included goal-setting, increased confidence, greater assertiveness, reduced frustration and anger with consequent impacts on service personnel and costs, increased autonomy in daily living, greater variety in activities, higher levels of engagement in community activities and organisations, increased literacy and numeracy, work related skills, changed employment and in one case, a decision to get married. For at least two, probably three and perhaps more of these decision-makers, outcomes are likely to reduce costs [in] the participating organisations.

Issue: when positive outcomes occur

An issue identified concerned the requirements needed for positive outcomes. Positive outcomes for participants required changes in three areas: voice, choice and control.
Positive outcomes for facilitators required practical and emotional support including:

- the development of new knowledge and skills
- role-modelling
- senior leadership support providing financial support and ‘moral authority’ for the program, and
- opportunities for and training in reflection to help refine their skills and deal with issues as they arise.

Positive outcomes for supporters were influenced by seeing their loved one being able to make decisions, by feeling more empowered about their own expectations about community organisations and service providers, and by the emotional satisfaction of supporting someone who they care about.

**Next steps**

The project evaluation endorsed the model, including further process refinements. However, it considered a cautious approach was necessary until better data on the cost-benefit was available. The report speculated on longer term savings but considered that there was a need for independent cost-benefit modelling on the supported decision making project as an urgent priority.

**9.3.4 Australian Capital Territory – 2013 ADACAS Pilot**

**Introduction**

The ACT Disability, Aged and Carer Advocacy Service (ADACAS) conducted a supported decision making (SDM) pilot between November 2012 and June 2013.\(^\text{243}\)

**Aim**

ADACAS’ described the aims of the pilot as to understand how people with a decision making impairment or whose decision making ability is undervalued, might be supported to make more decisions.

The ADACAS project took the South Australian trial as a starting point and sought to add to understanding as to how formal supported decision making might be accessed by a cohort of people with a broader range of decision making impairments and different support needs. This included people with complex communication needs, and those whose social isolation prevented them from identifying a natural decision support relationship. People needing support to make financial decisions were also included in the project.

**Methodology**

ADACAS explains the decision making model, adopted from the South Australian project, as follows:

In this model, supported decision making takes place in a freely given relationship, with a decision supporter providing as much support as necessary for a decision to be explored, weighed, made and recognised. The decision maker is always in control and is encouraged to approach decision making with the same expectations as a person that does not have a disability. ... This relationship is overseen by a monitor who acts as safeguard and coach.

A project coordinator oversaw the pilot to establish and oversee the research design, conduct community engagement, support the monitor, and develop processes and approaches to meet the support needs of the participants and supporters.

There was one monitor appointed, who had the roles of facilitating the creation of the supported decision making agreements, overseeing the relationships, and providing coaching support where needed. In its 2013 report, ADACAS recommends ‘[t]hat any supported decision making initiative include a paid monitor role to oversee and coach decision makers and decisions supporters’.

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\(^\text{243}\) The following account of the pilot program is based on: ACT Disability, Aged and Carer Advocacy Service (ADACAS), Spectrums of Support: A Report on a Project Exploring Supported Decision making for People with Disability in the ACT, September 2013.
Profile of the participants

Six people with varying degrees of decision making ability participated in the project.244 The pilot focused on people with cognitive disability. This term that is broader and more general than ‘intellectual disability’ and includes, for example Down syndrome.245

Operation of the project

The six participants were engaged between November 2012 and January 2013, and then remained in contact with the pilot until its completion date of June 2013. Two expressed a wish to participate during initial community engagement, two sought involvement on the recommendation of ACAT, and two were existing ADACAS clients.

The ADACAS 2013 report says:

This group was selected to represent a very broad range of decision making experiences and decision support needs. This provided the opportunity to apply the model in a range of untried contexts and respond to some of the issues encountered in the South Australian trial.

An important difference from the 2010-12 South Australian pilot was working with people with more significant support needs. In the ADACAS pilot several of the participants were not ‘decision-ready’ or were reluctant to express a decision. The pilot included these people to ‘explore what responses might be needed to secure formal decision support’ in that context.

ADACAS’s 2013 report notes that the initial interviews with the participants ‘revealed a diverse range of expectations and experiences of decision making. Each of these people enjoyed limited autonomy with lives largely lived in the service system and closely monitored by family’. Their decision making potential was ‘not well recognised’.

At the beginning of the pilot, three of the participants ‘were able to express their desire for change but lacked the experience, expectation or commitment to drive that change’. Another participant could not perceive that he had decisions to make, despite being on the cusp of needing to make key life decision after leaving school. The other two participants were ‘decision-ready’, and it was these two who were able to identify people in their lives who they wanted as ‘supporters’. Interestingly, both of these participants wanted to make financial decisions.

Decision making

Four of the participants used formal, written supported decision making agreements at some stage in the pilot.

In relation to the range of decisions covered by the pilot, ADACAS did not exclude financial decisions. Indeed, three of the six people wanted to make decisions about money and finances.

The participants had ‘a very diverse range of decision making experience’, highlighting how supported decision making responses need to be individualised in light of the experience and expectation of a broad range of potential supported decision-makers.

At the outset, three of the six participants said they did not have any decisions they wished to make. However, by the conclusion of the interview, with assistance to articulate their thinking, five of the six were able to express a desired decision.

245 Telephone discussion with Fiona May, Chief Executive Officer, ACT Disability, Aged and Carer Advocacy Service, 30 March 2015.
**Individual stories from the pilot (using pseudonyms)**

Toby was a client of ADACAS and was at risk of homelessness. He was unhappy with the decisions of his family guardians, and wanted to make more decisions himself. He expressed his willingness to make a decision under the pilot program, either about his accommodation, or to commence a review of his guardianship. Toby's guardians had the power to make accommodation decisions for him, and were observed to lack a consultative style, having made decisions neglecting to take Toby's will and preferences into account. Toby did not implement either decision within the pilot timeframe, but he remained hopeful about his potential to achieve more independence in decision making.

Natalie expressed dissatisfaction about her work arrangements. With support, she was able to articulate this as a prospective decision about changing her support and medication routine in relation to her working hours. Natalie could not find a supporter, so the project coordinator assumed that role. Natalie reported that the respect and willingness to listen shown to her by the coordinator, as her supporter, gave her the confidence she needed to voice her wishes to make decisions.

Claire wished to make a decision about her accommodation. However, she lacked decision making experience and had substantial difficulty understanding key concepts relevant to that decision. She did not have a supporter, so the monitor worked with her to develop her decision making skills and understanding.

**Outcomes**

The following table, from page 53 of the ADACAS 2013 report, summarises the pilot’s outcomes.
Both an internal report and an external review were positive.

The ADACAS 2013 report says: ‘There is now clear evidence that supported decision making initiatives are valuable and enable people with disability to be active decision makers who can exercise choice and control over the decisions that affect their lives’. The report also noted that: ‘Universally what was discovered was that each person’s capacity for self-determination was limited, not by their ability to make a decision, but by the support they received to exercise decision making’.

The review by the Queensland Office of the Public Advocate commented:

> While only based on a small sample, the ACT trial demonstrated that decision making support, whether informal or formal, can create positive change for individuals, families, service providers and the community more broadly. It also confirmed the need for a spectrum of decision making supports, from informal to formal, to meet the varied needs and capabilities of individuals.²⁴⁶

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²⁴⁶ Office of the Public Advocate (Queensland) 2014, see note 239, at page 25, citing ADACAS 2013 – see note 238.
Issue: securing supporters

An issue again was the considerable difficulty in finding supporters. Four of the six participants experienced social isolation, and the pilot explored how such people might access decision support. There were also tensions with family guardians when trying to secure supporters.

ADACAS reports that ‘[s]ecuring decision support was the most time consuming activity within the project’. Four of the six participants were able to identify potential supporters, but only two actually secured supporters.

ADACAS’s 2013 report emphasises a need for flexibility in terms of who a supporter or supporters might be, how long they might be in that role, and the scope of decisions they might be providing support for. Accommodating a ‘fluidity’ would bring supported decision making closer to how people without a disability make consultative decisions in life.

Participants Claire and Natalie each proposed trusted friends, both with mild intellectual disability and living in institutional settings, who they wanted as supporters. While those friends could clearly identify with many issues the participants faced, neither felt able to commit to the role, despite the offer of coaching and support from the monitor.

Claire approached several others she thought could be her supporter, but was ultimately unable to secure support within the timeframes and resources of the pilot. The project coordinator worked with Claire on developing understanding of her decision and of active decision making.

Natalie also approached her sister, who was also her joint guardian. While there was obviously potential here for tension between supported decision making and a ‘best interests’ approach by the sister, the project was interested to explore how supported decision making might work concurrently with guardianship; for example, their concurrent operation might reduce the guardian’s use, or misuse, of their powers. However, the sister declined to take on the role, feeling she would be compelled to make some substitute decisions, and that having to engage in supported decision making might doing so more difficult.

In light of the difficulty faced in finding supporters for isolated people, the organisers considered the possibility of professional decision support, acknowledging this would lack the interpersonal benefits of voluntary support. ADACAS itself took on the role of ‘supporter’ for one participant.

In light of ADACAS’s experience that professional decision support is a suitable substitute when voluntary support is unavailable, it recommended:

That supported decision making programs further develop a range of decision supporter models including freely given known supporters, volunteer introduced supporters and professional support.

Issue: guardianship

An issue was that with participants subject to existing long-term guardianship orders, guardian overreach (even in relation to small, day-to-day decisions) was evident, hampering opportunities to develop decision making experience by practising on the small decisions.

The ADACAS 2013 report notes:

Reassuring guardians that supported decision making could reduce vulnerability by building new skills while working in tangent with existing guardianship orders, helped create acceptance for the possibilities of supported decision making. One guardian, acutely distressed by the tension that being a family guardian placed on the relationship with his daughter, was inspired by the possibility that supported decision making could reduce the number of decisions he may have to make for his daughter.
9.3.5 Australian Capital Territory – 2014 ADACAS Pilot

Introduction

ADACAS conducted a further supported decision making pilot, this time focusing specifically on those with a dual diagnosis of psychosocial and intellectual disability.\textsuperscript{247}

Aim

ADACAS’s aims were:

- to build the decision making ability of people experiencing psychosocial and intellectual impairment to live the life that they choose by making more decisions for themselves, with decision support
- to build the capacity of their communities to recognise and support their decisions
- to explore how decision support might be made both accessible and sustainable.

Methodology

Recognising the impact of others in the lives of people with a disability on respect for their decision making potential, the pilot engaged with the communities of the participants, including family, guardians, support workers, and allied health professionals. A project coordinator attempted to identify and engage a ‘supporter’ for each participant from the people in the participant’s life. Introducing an ‘external supporter’ was an option if the person was socially isolated. If a supporter could not be found, or the participant preferred, the project coordinator provided one-on-one professional decision support. Although 1:1 participant-supporter relationship was part of the pilot structure, there was enhanced focus on bringing the participant’s community along too.

ADACAS specifically recommended investment in supported decision making training for those who share the lives of people with disability, to recognise the people’s rights and potential for decision making.

Profile of participants

The pilot had five participants, each of whom were experiencing a dual diagnosis of psychosocial and intellectual disability, and were recognised as having potential to be more engaged in decision making. Not all of them were concurrently subject to a guardianship order.

Outcomes

ADACAS’ 2014 report says that: ‘Overwhelmingly the outcomes indicate that people whose decision making ability is impaired can be more engaged in decision making with support and recognition’. The range and types of decisions in which participants gained decision making experience included: having more control in day to day life such as decisions about clothing and food; ending restrictive practices; planning for, choosing and purchasing a pet; social contacts; health care; paid supports; being more informed about medication; parenting; and work.

The 2014 report details how participants ‘grew through new experiences, emerging from exploration of real options driven by them. Decision makers were enabled to explore dignity of risk and the responsibilities that go with rights’. It also describes their ‘increased confidence as family members, including family guardians, service providers and health workers, recognised both their right and capacity to actively live the life that they choose’.

The report describes how the participants ‘increased expectation to be engaged in decision making, and experienced decision making skills including how to explore options, manage risks, consider responsibilities and consequences’.

In light of the success of this pilot, ADACAS recommends future supported decision making programs involve both the development of the capacity of individuals and the community at large to engage with supported decision making, and a concurrent 1:1 support structure for developing individual capacity.

\textsuperscript{247} Rea K. May F. Self-Determination and Cultural Change: A Report on Supported Decision Making for People Experiencing Psychosocial and Intellectual Disability ADACAS 2014; Telephone discussion with Fiona May, Chief Executive Officer, ACT Disability, Aged and Carer Advocacy Service (ADACAS), 30 March 2015.
Issues: guardianship

An issue for ADACAS was that while supported decision making can be used consistently with the Guardian and Management of Property Act to ensure least restrictive practice and the will and preference of the protected person, subjectivity around what might constitute a ‘significant decision’ proved an ongoing impediment to decision makers.248

The report details ADACAS’ suggestion that:

If decision making ability is assumed and a supported decision is attempted for each and every decision, the decision maker’s will and preference may at least have been established through the support process and subsequently used to inform any substitute decisions that may need to be made.

Issues: securing supporters

An issue was that the availability of professional decision support was essential in giving the opportunity to access supported decision making. Those with psychosocial and intellectual disability are especially vulnerable to isolation and a lack of friendships to draw on. They may also have particularly complex and sensitive decisions to make, such that voluntary support may not be workable. The 2014 report notes professional decision support ‘carried weight with clinicians and professionals and may, in some cases, be more readily available when needed’.

The 2014 report expresses some reservations about the utility of introduced professional support relationships:

Project time spent exploring introduced support relationships through a range of organisations who do good works in the community, as well as those established as volunteer networks, did not produce positive outcomes. Stigma around mental illness, lack of confidence in engaging with people with psychosocial disability and the complex nature of some decisions, created difficulty in gaining commitment from volunteers. Some decision makers themselves indicated their preference for a professional supporter. This preference reflected a lack of willingness to invest in personal relationship, the need for skill, knowledge and experienced supporters when making and fulfilling complex and significant decisions.

9.3.6 NSW: Supported Decision making Pilot 2013-2014

Introduction

The pilot was a joint initiative between the NSW Department of Family and Community Services, Ageing, Disability and Home Care, the NSW Trustee and Guardian and the NSW Public Guardian.249

Methodology

The main aims of the pilot were to learn more about how supported decision making relationships work, what tools and resources were useful and what issues may need to be considered for the broader application of a supported decision making framework.

The pilot also sought to develop and evaluate education material to raise the awareness of key stakeholders and the general community about supported decision making.

Profile of participants

Twenty-six participants joined the pilot, and six subsequently withdrew. All participants were drawn from a particular ADHC administrative region of Sydney. Five were concurrently under a guardianship order, and nine were concurrently under a financial management order.

One participant lived in public housing with drop-in support, 13 lived in the family home, and 12 lived in some form of residential accommodation, mostly group homes. Ten were spending their typical day in day programs, three were...

248 See also Guardianship Act, section 4.
249 The following account of the pilot program is based on the evaluation report – NSW SDM Pilot Report 2015 – see full citation at note 62.
in part-time or full-time work, five were in part-time work and involved with day programs, two were in a transition to work program, one was in school, and the remaining five had no formal daytime activity.

Twenty-two of the participants had intellectual disability as their primary disability, and two had an acquired brain injury as their primary disability; the primary disability of the other two participants was not disclosed. Twenty-two of the participants were verbal, and the remaining four were verbal with support.

Profile of supporters

There were 19 people acting as supporters to 16 of the participants. Ten of those supporters were paid service providers, seven were family members, one was a friend, and one was a paid advocate. The pilot facilitators took on the supporter role for another six participants. Four participants withdrew from the pilot without a supporter having been nominated.

The pilot involved training and assistance for supporters, including direct engagement with facilitators, ongoing coaching and support, and a workshop.

Outcomes

The report summarised the pilot outcomes as follows:

The pilot demonstrated that [supported decision making, ‘SDM’] could be successful for a diverse group of people with a disability and varied support needs and circumstances.

...Individuals showed increases in confidence and sense of control in their own lives and were making decisions in areas where they had not made decisions before.

The barriers to SDM were largely not due to the person's disability but to the lack of supports that were immediately available to them. Circumstances of social isolation, lack of power and unfamiliarity with making decisions, low expectations by others, power imbalance in relationships and the need for investment of time within which to do SDM all create challenges for SDM.

Key enablers were 1:1 support and training with a trusted individual and the time available to work thoroughly through the decision making process, together with role modelling, mentoring and training of people in the supporter role and a shift in the ‘mindset’ of the broader service system providing services to the individual.

Issue: ‘Decision readiness’

An issue was that for participants to reach the point of ‘decision readiness’, described as having the knowledge and skills to make an identified decision:

[F]acilitators in the pilot were required to invest considerable time working 1:1 with each decision maker to build their capacity to be decision-ready. Supporters too required mentoring in how to assist in this capacity building.

The experience of the pilot was that there were significant challenges to decision readiness, including often limited literacy and communication skills, lack of confidence and of course difficulty in securing a supporter. The report noted that ‘[d]ecision makers may have a more realistic understanding of the decision making process after experiencing SDM’ and cautioned that a person’s ‘communication needs and style need to be established and accommodated as a first step to SDM’.

Issue: Tools and Resource Materials

An issue was the lack of usefulness of the materials and resources developed for the pilot. These were:

- My life, my decision – a booklet for the supported decision making pilot: designed for participants and available in Standard English and Easy to Read;
- Supported Decision Making Pilot Handbook (2013) – a handbook for supporters who were to help participants make decisions, and for carers and services providers whether or not they were being supporters;
- Tools and Resources Kit: a compendium of reading materials, tools and worksheets drawn together in a folder from local and overseas source, with website links to additional information.
It was expected that these resources would ‘reduce the need for face-to-face facilitation’, however decision makers and supporters both reported that they provided limited assistance. They were not seen as sufficient to enable supported decision making on their own. The evaluation noted that:

The pilot demonstrated that the facilitator role was crucial to the achievement of supported decision making. Facilitators needed to spend significant time working on a 1:1 basis to support both decision makers and supported to progress the decisions which had been identified for the pilot.

The volume of material was seen as overwhelming, and the low literacy levels of many decision makers meant much was not really suitable. The exception to this was the Easy to Read booklet, which ‘appeared to serve as a focal point and added legitimacy to the supported decision making process for some decision makers’.

While some supporters used some of the resources, overall the ones developed in the pilot were of most use to the facilitators, who used them extensively.

**Issue: Supporter selection**

An issue again was supporter selection:

Choosing a supporter was often one of the first decisions made by decision makers, with assistance from a facilitator. Finding supporters proved to be more challenging than expected. In six instances, the facilitators acted directly as supporters. This is a fundamental issue for supported decision making, for without a supporter there can be no ‘supported’ decision making.

The pilot facilitators, in discussing with prospective participants who in their networks might be a suitable supporter, tried not to influence the person’s decision about who would be appropriate. Some people invited to be supporters declined to do so, on the basis that, in their opinion, they were already implementing supported decision making practices.

The report reported that ‘[l]ocal choice and staff and organisation receptiveness combined to make the process of supported decision making successful’ for the 10 participants who had a paid supporter, and noted ‘the potential need to build the capacity of disability service providers to become a source of facilitators or supporters’.

Some of the participants had group home staff as their supporter. Some of those staff indicated they felt time pressures in relation to the supporter role, and would have preferred to have had more time supporting the participants and having that recognised by management. The report states the need for recognition of time implications for service providers in the case of staff from those organisations taking on a decision making supporter role.

Some difficulties did arise during the pilot in relation to family member resistance to a decision made by the participant with support from a paid supporter. The report further raises the need for conflict of interest risk to be addressed in the case of paid supporters, in any future supported decision making schemes.

In relation to the use of the pilot program organisers, or ‘facilitators’, as supporters, the report says the high reliance in this pilot on this source of supporters indicates ‘that any system of SDM requires the capacity to access supporters who are not already part of the networks of individuals who require support with decision making’. The instances where facilitators did take on the supporter role in this pilot were not planned, and so there was substantial time spent by the facilitators on getting to know the relevant participants’ preferences, communication styles and decision making styles.

In relation to the use of family members as supporters, not all family members who were approached were willing to take on the role in this pilot. Indeed, one participant’s withdrawal from the pilot corresponded with her mother declining to assume the formal supporter role.

Difficulties encountered in the pilot from the use of family member supporters included conflict of interest, and resistance to the person’s desire to make more decisions for themselves. The report noted that readiness and training may be relevant factors in any reluctance of family members to become formal ‘supporters’, and suggests targeted training which increases familiarity with supported decision making principles and processes as a potential remedy for this.
The report made the point that ‘[s]ome individuals will be unable to identify their own supporters and will need access to an appropriate mechanism through which to find [them]’. It added that ‘[a]ccess to an ‘independent’ supporter can be helpful for some individuals, for example using an advocate’.

**Issue: Other barriers to a successful supported decision making experience**

An issue was a series of unanticipated barriers to successful supported decision making including lack of interest in supported decision making, tendencies especially among service providers to prioritise duty of care over ‘dignity of risk’, and cultural norms in some family environments. The report emphasised that any future supported decision making initiatives will need a focus on the attitudes of family members and service providers who may become formal supporters, not just in training about the mechanics of supported decision making. It also said that ‘[m]odelling and mentoring (such as that undertaken by the facilitators in the pilot) can assist with both training and attitude change’.

The report said that:

Dissemination of the principles of supported decision making as well as information about processes which are helpful will be needed to enact attitudinal and practice changes amongst stakeholders who provide supports to people with a disability and the broader community.

**Issue: Financial decision making**

An issue was that most participants said they made few if any of their own financial decisions. After a couple of months, over half of participants said they now made some financial decisions. However, only two of the participants concurrently under financial management reported an increase in financial decision making at that stage.

The report says:

More work needs to be undertaken to develop supports which can assist individuals who are under financial management to take greater responsibility for their own financial decision making.

There needs to be further investigation of the barriers which prevent individuals under financial management from exercising supported decision making.

**Issue: Implementation of decisions**

An issue was that many supporters lacked the time to assist with implementation of supported decisions made by the participant. This problem was especially acute for paid supporters.

In some instances, supporters felt lacking in ‘authority’ to assist with implementation. The problem was faced similarly by participants, who on occasions decided against implementing their decision out of fear of damaging relationships. On some occasions, participants did not want to involve the very people who needed to be involved for implementation to be successful, such as family members. The report draws from these observations about relationships and sensitivities that ‘supporters can face dilemmas about where and when not to intervene to guide decision makers in the implementation of their decisions’.

It is notable that ‘in most cases [participants] chose to preserve relationships instead of pursuing a decision that their supporter didn’t agree with’.

Further, some participants had implementation of their decisions frustrated by power imbalances between them and service providers.

The report urged a focus, in any future supported decision making initiatives, on support for the implementation of supported decisions made, and recommended that ‘[w]eighing up choices and the impact on others should be part of training in [supported decision making]’.

**Issue: Guardianship and financial management issues**

An issue was that where a guardian was in place, the guardian reported that the time taken to make financial decisions was longer than would be expected in the absence of a supported decision making arrangement.

The experience of the pilot participants concurrently under financial management suggests that more financial literacy development may have assisted increased financial decision making.
The report cautions:

Adoption of supported decision making processes for individuals who are under formal guardianship will require more coordination between the individual and their supporter and their guardian/financial manager. There is a time implication for this.

**Recommendations**

The report recommended the development of a supported decision making framework that recognises the need for ‘flexible support arrangements’, including family members, paid supporters and advocates; that recognises the need for ‘dedicated supporter time’; and that addresses the risk of conflicts of interest where a paid service provider or family member takes on the supporter role.

**9.3.7 Victoria: Office of the Public Advocate**

**Introduction**

The Victorian Office of the Public Advocate (OPA) ran an 18-month supported decision making pilot project funded by the Victorian Law Foundation; an evaluation of which was released in late March 2016.

Drawing on that experience, in September 2015 OPA began a 12-month collaborative supported decision making project (OVAL) with Victorian Advocacy League for Individuals with Disability Inc (VALID) which:

- aims to recruit, train and match volunteer supporters in Victoria’s Barwon South region with 60 socially isolated people with decision making disabilities who wish to receive support with decision making about their National Disability Insurance Scheme (NDIS) support plan.
- Volunteers will assist participants to build their capacity to make autonomous and informed decisions about their NDIS support plan.
- The OVAL Project is funded by the National Disability Insurance Agency (NDIA), which has identified that further development is required for people with disability to assume significant choice and control over their lives.
- The OVAL Project will also develop a ‘model of practice’ for supported decision making for scheme participants, which include resources and tools for participants and supporters.

**Methodology**

The pilot project focused on a core participant-supporter relationship. The pilot was not designed with a specific ‘monitor’ role in mind.

**Profile of the participants**

There were 18 participants recruited. OPA recruited adults who had an intellectual disability and were socially isolated and/or had few or no informal supports. The age range of participants was from late teens through to late 60s.

Participants’ accommodation situation varied. Some lived at home; some in group homes i.e. specialist homes for people with intellectual disabilities, and some in residential services i.e. community-run facilities providing meals etc. Only a few of the participants actually went to day programs and the like, in contrast to the 2010-12 South Australian pilot’s participants.

About half a dozen participants had concurrent guardianship orders in place. In contrast to the situation in the South Australian and the ACT, this worked well for all of them, with very positive outcomes.

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250 Unless otherwise noted, the following account of the pilot program is based on email and telephone discussion with Brenda Burgen, Supported Decision making Coordinator, Office of the Public Advocate (Victoria) on 16 and 17 March 2015, and updated through email contact in January-February 2016. Inspiring stories of success attributable to the project, with tangible steps taken towards participants’ achieving their goals and boosting their confidence are set out in a presentation on 10 December 2014 to the 8th La Trobe roundtable on disability policy: Burgen B. Chesterman J. Supported Decision Making and the Office of the Public Advocate.


252 The project is described on VALID ‘s website [http://www.publicadvocate.vic.gov.au/advocacy-research/supported-decision-making](http://www.publicadvocate.vic.gov.au/advocacy-research/supported-decision-making)
The decision to recruit ‘isolated’ participants stemmed from a desire to avoid the 2010-12 South Australian pilot’s situation, where potential participants missed out because ‘supporters’ could not be found from circles of family and friends. This drew on the experience in the sector that a person with an intellectual disability who does not have family support will be especially vulnerable to poor quality of life. The notion of ‘isolation’ broadened as the project coalesced, and the organisers set out to find people who were socially isolated and/or had few or no informal supports.

**Profile of the supporters**

Eighteen volunteer supporters were recruited, none of whom were previously known to the participants. Each supporter was matched with a participant, with one taking on the supporter role for two participants.

It was observed that recruiting volunteers who did not know the participants addressed the tension that can occur when family members who take on the supporter role may be resistant to the person’s wishes.

**Decision making**

The pilot was designed to cover accommodation, lifestyle and health decisions. About half of the participants had an idea at the beginning about what kinds of decisions they wanted to make. That shifted as the trial went on and participants have practised and developed their decision making processes.

There was no obligation to draw up any formal documentary agreement between participant and supporter. Only a few supporters expressed interest in doing this and a straw poll of people involved in the pilot found that mandating such a formal agreement was thought not to be helpful.

**Interim assessment of progress / outcomes**

The supporters were able to support participants to achieve a wide range of interventions by:

- breaking the decision making process into understandable and achievable steps
- obtaining relevant information and presenting it in an accessible way
- explaining and assisting with weighing up relevant information and considerations
- assisting the participant in problem-solving
- assisting the participant to act on their decision
- attending initial appointments with the participant, and
- assisting the participant to link in with self-advocacy or other ongoing support

One lesson from the pilot was that supported decision making can be less successful if a person is somewhat ambivalent about the process or about engaging with the supporter. Developing or having a good relationship between the supporter and the decision maker was important.

**Key findings of the evaluation of the pilot**

Volunteer supported found their interactions with the broader Disability Services context often problematic. Almost all of them expressed frustration that these services often slowed down or impeded the decision making process for the participants. Family members also often acted as a negative external factor – many having difficulty ‘letting go’ to enable the participants to experience the decision making process and practice their skills. There were also difficulties with participants who wanted to make decisions, but were having difficulty breaking away from what their families wanted.

The 12-month timeframe and commitment of support was not considered satisfactory, as participants were not ready to ‘go it alone’ or even to reduce contact. The process ended and the participants were then going to be left without decision making assistance and support. This was, in part, because the plan of the pilot had been to address social isolation, but this had not worked well enough by the end of the pilot.

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The supports felt that their role definition had not been clear enough, and in some cases, support had moved into advocacy. The supports felt that the organisation running the new OVAL project, VALID, had better delineated three main advocacy roles:

- Standing behind – providing training, information and advice to empower people to self-advocate;
- Standing beside – providing assistance (offering prompts and reminders) to assist the person raise issues with others; and
- Standing before – providing representation (acting or speaking on behalf of the person).

These definitions made it clear that support and advocacy overlapped and that some advocacy may be necessary for the supporter to do their job. The new OVAL project will be addressing these issues.

**Other developments in Victoria**

Following the release of the VLRC’s Final Report on Guardianship in 2012, the Victorian Parliament introduced amendments to give a legislative basis for supported decision making under the Mental Health Act 2014 (Vic) and the Power of Attorneys Act 2014 (Vic), and a new Guardianship and Administration Bill 2014 which has subsequently lapsed. The new Mental Health Act in Victoria includes a provision in its principles that states:

11(c) persons receiving mental health services should be involved in all decisions about their assessment, treatment and recovery and be supported to make, or participate in, those decisions, and their views and preferences should be respected;

However, there is little else in the Act that sets out how this will be put into effect.

Part 7 of the Powers of Attorney Act 2014 (Vic), sets up a new arrangement called a Supportive Attorney, to allow someone to be appointed to provide assistance in decision making. The lapsed Guardianship and Administration Bill had proposed a range of mechanisms including a Supportive Guardian.

The Victorian Department of Human Services has prepared a set of materials for service providers and decision makers on supported decision making in preparation for the introduction of the NDIS. This included a quick reference guide for disability support workers, and a booklet for service providers.


29 July 2016
9.4 Lessons from the Pilots

These pilots provide many lessons for the future, including three primary mechanisms for changing the understanding of the decision making ability of those who have impaired decision making ability:

- challenging history – particularly negative expectations and assumptions
- permission to try – a recognition that some things will succeed and some will not and it’s alright to ‘give it a go’
- development of skills to work differently – for decision-makers, supporters, families and service providers.²⁵⁶

Transition to a will, preferences and rights based system of supported decision making can be a positive learning opportunity for everyone if the concerns and fears of carers, families and service providers are acknowledged and addressed in the transition.

Other lessons from the pilot studies include:

- Participation: There needs to be considerable flexibility in finding supporters. There need to be flexibility in terms of who a supporter or supporters might be, how long they might be in that role, and the scope of decisions they might be providing support for. Supported decision making programs need to develop a range of decision supporter models including known supporters, volunteer supporters and professional supporters.

- Publications: Easy-to-read Standard English fact sheets and web accessible resources are essential. They can serve as a focal point to the supported decision making process.

- Training: Training needs to focus not just on the mechanics of supported decision making process but also on addressing attitudes of family members and service providers, including lack of interest, low expectation on decision making capacity, defaulting to a duty of care approach, and unsupportive cultural and family norms.

- Implementation: There needs to be adequate provision in terms of time and resources to assist with the implementation of supported decisions made by participants.

It is the Council’s view that a significant period of transition is required to effectively implement the change to supported decision making, as set out in Recommendation 11 above. Procedural and preparatory changes drawn from the experience of supported decision making pilots conducted in the ACT and other jurisdictions should guide this transition.
PART 10: RELATED MATTERS

The UN Convention requires that people with disabilities have the right to recognition as ‘persons before the law’ in all circumstances, and that they enjoy legal capacity on an equal basis with all other people. While the Council’s Terms of Reference focus on the current Guardianship Act and supported decision making, it is clear that the requirement for equal recognition need to be evident in other ACT legislation.

10.1 Amendment of legislation that relates to legal capacity

The Council was made aware through its research for this reference that the terms ‘legal capacity’ and ‘mental capacity’ are used (sometimes interchangeably) in many pieces of legislation in the ACT, in ways which do not comply with the Convention’s intention. There is significant variation, ambiguity and confusion about what is constituted by ‘capacity’ in these various provisions. In some instances, ‘capacity’ refers to legal personhood; in other instances, ‘capacity’ is concerned with decision making ability, or ability to do some other task specified in the legislation. Appendix 2 includes lists some of the ACT legislative provisions that instance this.

In order to comply with the spirit of the UN Convention, ACT legislation needs to be reviewed to ensure consistency in the treatment of all people as equal before the law. Any legislative limitations on this equality must be framed in a way which is consistent with a person’s ability to carry out the specific functions under the relevant legislation (with such support as necessary, if that ability is impaired).

Recommendation 14:

The Council recommends that the Government undertake an audit of ACT legislation to identify where amendments are required to give effect to Article 12 of the UN Convention on the Rights of Persons with Disabilities to ensure that all people (including those with disabilities) are treated equally before the law and, where necessary, support is available to enable this to occur. Legislative language needs to be framed in terms of ‘ability with support’, rather than ‘capacity’ and ‘incapacity’. Whenever the terms ‘legal capacity’ or ‘mental capacity’ are used, or the word ‘capacity’ is used to indicate ‘legal capacity’ or ‘mental capacity’, the term ‘decision making ability’ may need to be used instead. Similarly, whenever the terms ‘legal incapacity’ or ‘mental incapacity’ are used, or the word ‘incapacity’ is used to indicate ‘legal incapacity’ or ‘mental incapacity’, the term ‘impaired decision making ability’ may need to be used instead.

10.2 Future review of criminal justice legislation and practice

The Council notes that there are implications for criminal justice practice and procedure in the UN Convention on the Rights of Persons with Disabilities that are outside the Council’s Terms of Reference and have not been considered. There is likely to be strong public interest that criminal justice practice and procedure also made compliant with the principles of the UN Convention.

The Australian Law Reform Commission has made recommendations in this area. While the Council’s current recommendations do not address whether reform to the criminal justice system is necessary, a separate inquiry to consider this is warranted.

Recommendation 15:

The Council notes that there are implications for criminal justice practice and procedure in the UN Convention on the Rights of Persons with Disabilities that are outside the Council’s Terms of Reference and have not been considered. The Council recommends that consideration be given to the reform of the law in this area.

10.3 Involuntary treatment, restraint and seclusion

Many of the processes which have traditionally been used where someone’s decision making capacity was impaired and their actions were seen to cause significant risk to self and others have involved the use of force against that person’s will. It is hoped that the context of supported decision making and new understandings of how to work with people with impaired decision making who may experience psycho-social difficulties will minimise situations where force will be necessary. However, the Council considers, it is important to address these situations clearly. The most common areas where force is used relate to involuntary treatment, restraint and seclusion, and the placement of someone in accommodation against their will for protection of self or others.
In their Submission ACT Health noted the lack of clarity around the legal position of the use of force by a guardian where the protected person does not want to go to a facility for treatment, does not want to move to different accommodation, or does not wish to receive specific treatment, and where the guardian considers it to be in their best interests for these events to occur. The submission states:

> [The] problem with the guardian’s section 7(3)(e) power to consent to treatment … is that it seems unlikely to extend to the guardian being permitted to use reasonable, proportionate force to ensure the person receives treatment for so-called ‘physical’ conditions, even when a doctor would reasonably say that the person needs that treatment to avert impending death or severely compromised health. Whenever treatment is provided to a person on the basis of substituted consent, at least two of the person’s human rights, provided by common law and the Human Rights Act 2004 … are engaged: the person’s right to privacy and right to be free from cruel, inhuman and degrading treatment. The latter right incorporates the right not to be subjected to medical treatment without the person’s free consent.257

> ACT Health recognised that under the Mental Health Act, supported decision making now applies first, but that if this does not result in the person giving consent, when their life is at risk and their decision making ability is accepted as impaired, there are procedural guarantees that permit force to be used to provide treatment. None of these safeguards exist in the current Guardianship Act in relation to decisions about the use of force. The submission goes on to say that:

> The European Court of Human Rights has ruled that fundamental to the right to privacy is the right to physical integrity and that the latter connotes a right to refuse consent to medical treatment. The Court also ruled that coercive treatment that is therapeutically necessary will not infringe the prohibition on inhuman and degrading treatment, where that necessity can be ‘convincingly shown to exist’ and the treatment is given in the context of proper ‘procedural guarantees’.258

While procedural protections exist under the Mental Health Act for forced health care treatment in the therapeutic context, there are no statutory protections for these kinds of processes in residences, in aged care setting or in disability accommodation. Some submissions in the consultation process described the use of such procedures in relation to older people and people with disabilities. While it is clear from international human rights law that there are circumstances where the expressed wishes of someone with impaired decision making ability may be overruled when their life is at stake or their future well-being seriously threatened, the level of evidence that is required is establish this is quite high – in essence the concept of ‘medical necessity’ must be ‘convincingly shown to exist’.259

Because these circumstances are generally triggered by a question about someone’s ability to make decisions, where inappropriate decision are likely to result in significant harm or death, any use of force in these circumstances should require the oversight of an external body, and in most cases, approval should be given by a publicly accountable decision making body such as ACAT.

Further, the Council considers that the wording of the UN Convention in Article 12(4) requires that, in these cases, the rights of the person can be adequately protected by:

> Effective safeguards to prevent abuse in accordance with international human rights law;
> Measures that are free from conflict of interest and undue influence;
> Measures that respect the will, rights and preferences of the person;
> Measures that are proportional and tailored to the person’s personal circumstances;
> Any limits on freedom applying for the shortest time possible; and
> Regular review by a competent, independent and impartial authority of judicial body.

In the new legislative framework, the Council considers that such procedural protections should be provided for any circumstances where force is necessary to deliver treatment, to restrain someone or seclude someone. This should ensure that any of these actions are preceded by assistance to support the person making their own decision, and that any actions against their will and preferences, complies with their rights, including being proportional, time limited, convincingly shown to be necessary and determined by ACAT and overseen, where necessary, by the Public Advocate. The model of scrutiny and protection included in the Mental Health Act, provides a useful starting point for suitable model provisions in this regard. However, the Council considers further work is required to properly address this area and ensure that appropriate law, practices and policies are applied across people in all circumstances. In consultations with the Council, examples were given of the imposition of force occurring under guardianship

257 Submission 21, Appendix A, page 5, paragraph 25.
259 Herczegfalvy v Austria (1992) 15 European Human Rights Reports 437 at paragraph 82.
arrangements, with people in aged care facilities, people in disability services and people in health services, which were not regulated by legislation.

There is a need for careful consideration of the most effective ways of ensuring the protection of people with impaired decision making who are considered to be at risk of harming self or others and therefore potentially subject to the need for the imposition of force. The Council considers that further work is required to develop the most appropriate approach to such coercive or restrictive practices, including in circumstances of compulsory treatment, restraint, seclusion, mandatory living arrangements and other controls, which may be seen as breaching the rights of a person with impaired decision making ability.

Recommendation 16:

The Council considers that strong and consistent safeguards are required to regulate any restrictive or coercive practices applied to people with impaired decision making ability. While the Council is attracted to using a similar set of requirements as are set out in the Mental Health Act 2015, the Council recommends that a further review is needed to ensure a proper consideration of the complex issues raised by these questions,
**APPENDIX 1: List of Submissions received**

1. John Smith - Individual
2. Andrew Taylor, Public Trustee for the ACT
3. Individual via ADACAS
4. Helen Bateman, Sheryl Harrison, Hamish Jeffrey, Calvary Hospital
5. Australian Lawyers for Human Rights
6. Advocacy for Inclusion
7. Centre for Disability Law and Policy - National University of Ireland Galway
8. Phyllida Ives - individual
9. Gordon Ross - individual
10. Women with Disabilities ACT
11. ACT Human Rights Commission
12. Mental Health Community Coalition ACT Inc
13. COTA ACT
14. Leading Age Services Australia
15. ACT Law Society
16. ADACAS
17. Individual Guardian/Carer
18. ACT Mental Health Consumer Network
19. Susan Penn-Turrall, Principal Guardian and Deputy Public Advocate of the ACT
20. Health Directorate, ACT Government
APPENDIX 2: Legal Capacity, the UN Convention and implications for other ACT legislation

Introduction

The message conveyed to the Council in its inquiry is that decision making ability should be assumed in all people. Further, that as a consequence the issue of legal incapacity arises only when all possibilities for supported decision making are exhausted. This position is sharply at odds with the current approach taken in laws in the A.C.T, where legal capacity and incapacity are treated as binary opposites. This Part identifies the legislation where, as currently drafted, ‘loss of capacity’ triggers certain consequences which are at odds with these assumptions. By comparison, a UN Convention-compliant approach would recognise that, with support, most people most of the time will have decision making ability, and that any necessary substitute decision must be made in accordance with a person’s will preference and rights. The changes proposed eliminate the concept of ‘loss of capacity’ and the consequences that flow from this.

Recommendation 14 set out in the Report addresses this:

The Council recommends that the Government undertake an audit of ACT legislation to identify where amendments are required to give effect to Article 12 of the UN Convention on the Rights of Persons with Disabilities to ensure that all people (including those with disabilities) are treated equally before the law and, where necessary, support is available to enable this to occur. Legislative language needs to be framed in terms of ‘ability with support’, rather than ‘capacity’ and ‘incapacity’. Whenever the terms ‘legal capacity’ or ‘mental capacity’ are used, or the word ‘capacity’ is used to indicate ‘legal capacity’ or ‘mental capacity’, the term ‘decision making ability’ may need to be used instead. Similarly, whenever the terms ‘legal incapacity’ or ‘mental incapacity’ are used, or the word ‘incapacity’ is used to indicate ‘legal incapacity’ or ‘mental incapacity’, the term ‘impaired decision making ability’ may need to be used instead.

Other Acts

Many Acts deal with ‘legal incapacity’ and ‘legal capacity’ in various contexts, including laws relating to the making of contracts and other financial transactions, to the age of majority and voting, to criminal responsibility, and to giving evidence and participation in legal processes.

Other Acts refer to responsibilities consequent upon adult guardianship. These will also need amendment with the changes required to current guardianship arrangements, to ensure that they are consistent with the proposed framework and language. A large number of Acts and regulations make references to adult guardianship as listed in Table 2.

A further group of Acts refer to physical and mental incapacity, where this affects people’s ability to exercise various responsibilities, eg judges, board members, association public officers, teachers, public servants, other office holders. Some of these have been enacted more recently and refer to the impact of impairments on the capacity to do specific tasks.

However, many use the word ‘incapacity’ rather than impairment, which can result in confusion between legal capacity and the physical or mental ability to carry-out a particular function or responsibility. Reform of the language and a focus on the impact of the impairment on the ability to do the task is crucial to ensure that people with
disabilities are not discriminated against in legislation. A large number of these Acts and regulations refer to ‘legal capacity’ and incapacity:

- Age of Majority Act 1974
- Children and Young People Act 2008
- Civil Law (Wrongs) Act 2002
- Cooperatives Act 2002
- Crimes (Child Sex Offenders) Act 2005
- Crimes Act 1900
- Criminal Code 2002
- Domestic Animals Act 2000
- Electoral Act 1992
- Evidence Act 2011
- Lands Acquisition Act 1994
- Perpetuities and Accumulations Act 1985
- Sale of Goods Act 1954
- Trustee Act 1925
- Victims of Crime (Financial Assistance) Act 1983
- Wills Act 1968
- Workers Compensation Act 1951

Other legislation adopts the common law position in relation to capacity, eg s 7(1) of the Sale of Goods Act 1954 provides that ‘Capacity to buy and sell is regulated by the general law concerning capacity to contract and to transfer and acquire property’. Other legislation relies on the presumption of capacity, eg section 12 Evidence Act 2011.

Other legislation anticipates a guardian’s acting when a relevant person lacks legal capacity, eg section 55A of the Domestic Animals Act 2000, which allows a victim to apply for information to be made about a dog who has attacked a person, provides that ‘if the victim does not have legal capacity—the victim’s parent or guardian’ may apply. See also in this regard:

- Limitation Act 1985 s 31 ‘Notice to proceed’
- Crimes (Forensic Procedures) Act 2000 s 10 ‘Meaning of volunteer’
- Land Titles Act 1925 s 18 ‘Land brought under Act’
- Disability Services Act 1991 s 8F ‘Register of approved disability accommodation’
- Corrections Management Act 2007 Dictionary: ‘family member’
- Retirement Villages Act 2012 s 113(5) ‘Attendance at meetings of residents’
- Coroner’s Act 1997 Dictionary: ‘member of the immediate family’

Other legislation associates ‘capacity’ with the performance of the inherent requirements of employment, eg section 63(1)(iii) of the ACT Teacher Quality Institute Act 2010 provides for suspension or cancellation of a person’s registration or permit to teach if the person ‘has become mentally or physically incapacitated and the incapacity prevents the person from performing an inherent requirement of their job as a teacher’; s19D of the Building Act 2004 provides for resignation as a certifier ‘because of mental or physical incapacity’. See also in this regard:

- Public Sector Management Act 1994 s143 ‘Redeploy or retire officer from service’; s 146 ‘Unattachment of officers’
- Unit Titles (Management) Act 2011 s54 ‘Manager – ending contract’, s 64 ‘Service contractor – ending contract’
- Civil Unions Act 2012 s 15 ‘Registration of civil union celebrants’
- Agents Act 2003 s 27 ‘People disqualified from being licensed’, s 51 ‘People disqualified from being registered’.
- Other legislation refers to capacity in relation to holding office:
> Aboriginal and Torres Strait Islander Elected Body Act 2008
> ACT Civil and Administrative Tribunal Act 2008
> ACT Teacher Quality Institute Act 2010
> Agents Act 2003
> Anglican Church of Australia Constitutions Act 1902
> Anglican Church of Australia Trust Property Act 1917
> Anglican Church of Australia Trust Property Act 1928
> Architects Act 2004
> Associations Incorporation Act 1991
> Auditor-General Act 1996
> Building Act 2004
> Canberra Institute of Technology Act 1987
> Children and Young People Act 2008
> Civil Law (Wrongs) Act 2002
> Civil Unions Act 2012
> Climate Change and Greenhouse Gas Reduction Act 2010
> Commissioner for Sustainability and the Environment Act 1993
> Construction Occupations (Licensing) Act 2004
> Construction Occupations (Licensing) Act 2004
> Director of Public Prosecutions Act 1990
> Domestic Relationships Act 1994
> Domestic Violence Agencies Act 1986
> Education Act 2004
> Electoral Act 1982
> Emergencies Act 2004
> Family Provision Act 1969
> Financial Management Act 1996
> Government Procurement Act 2001
> Health (National Health Funding Pool and Administration) Act 2013
> Health Act 1993
> Human Rights Commission Act 2005
> Independent Competition and Regulatory Commission Act 1997
> Information Privacy Act 2014
> Inquiries Act 1991
> Judicial Commissions Act 1994
> Justices of the Peace Act 1989
> Law Officers Act 2011
> Legal Aid Act 1977
> Legal Profession Act 2006
> Legislative Assembly (Office of the Legislative Assembly) Act 2012
> Magistrates Court Act 1930
> Mental Health (Treatment and Care) Act 1994
> Nature Conservation Act 1980
> Nature Conservation Act 2014
> Official Visitor Act 2012
> Ombudsman Act 1989
> Planning and Development Act 2007
> Public Advocate Act 2005
Other legislation allows for action to be taken against a person ‘for misbehaviour or physical or mental incapacity’, eg:

- s 44 of the Education Act 2004 ‘Ending of appointment of members of school board’
- Sch 4 s 4.43 Civil Law (Wrongs) Act 2002 ‘Vacancy in office of member [of the Professional Standards Council]
- 64 Associations Incorporation Act 1991 ‘Vacancy in office of public officer’

Other legislation makes provision for a person who lacks legal capacity, eg:

- s 164 Cooperatives Act 2002, ‘Registration as administrator of estate on incapacity of shareholder’
- Sch 2, s 2.1 Cooperatives Act 2002 ‘Requirements for all cooperatives’
- s 137 Crimes (Child Sex Offenders) Act 2005 regulation making power for when ‘an offender does or does not have the legal capacity to understand information’
- ss 13 and 14 Evidence Act 2011 ‘Competence – lack of capacity’
- s 67 Crimes Act 1900 ‘Consent [in relation to sexual offences]’
- s 375 Crimes Act 1900 Summary disposal of certain cases [in the Magistrates Court]’
- s 81 Electoral Act 1992 ‘Objections to enrolment’
- Crimes (Child Sex Offenders) Act 2005132 ‘Definitions – pt 5A.6 ‘person with a mental disability’
Other legislation refers to guardians and guardianship, eg:

- ACT Civil and Administrative Tribunal Act 2008
- Administration and Probate Act 1929
- Coroners Act 1997
- Civil Law (Property) Act 2006
- Corrections Management Act 2007
- Crimes Act 1900
- Crimes (Child Sex Offenders) Act 2005
- Crimes (Forensic Procedures) Act 2000
- Disability Services Act 1991
- Electoral Act 1992
- Health Records (Privacy and Access) Act 1997
- Intoxicated People (Care and Protection) Act 1994
- Land Tax Act 2004
- Land Titles Act 1925
- Limitation Act 1985
- Magistrates Court Act 1930
- Partnership Act 1963
- Retirement Villages Act 2012
- Road Transport (Third Party Insurance) Act 2008
- Terrorism (Extraordinary Temporary Powers) Act 2006
- Trustee Act 1925
- Workers Compensation Act 1951

Other legislation anticipates circumstances that involve legal incapacity, eg:

- Retirement Villages Act 2012 s 187 ‘Ending of residence contract on medical grounds’, s 228 ‘ACAT decision in relation to proposed buyer’, s230 ‘ACAT decision in relation to proposed tenant or subtenant’
- Children and Young People Act 2008 s 645(4) ‘Agreement to transfer an order’
- Victims of Crime (Financial Assistance) Act 1983 s8 ‘Legal incapacity – criminal intent’
- Partnership Act 1963 s 40 ‘Dissolution by Supreme Court’
- ACT Civil and Administrative Tribunal Act 2008 s 43(3)(e) ‘Executing a warrant’
- Workers Compensation Act 1951 s 33 ‘Payments to people with legal disabilities’
- Magistrates Court Act 1930 s 66(4) ‘Executing a warrant’
- Electoral Act 1992 s 81(11) ‘Objections to enrolment’