TELL US WHAT YOU THINK
ADULTS MAKING DECISIONS IN THE ACT
Reform of guardianship arrangements for adult people with disabilities in our community
RESPONSE BOOKLET - MARCH 2015
1. YOUR EXPERIENCE OF GUARDIANSHIP IN THE ACT

The current law is called the Guardianship and Management of Property Act 1991. Under that law, guardianship is a way of helping adult people who can have difficulty making decisions for themselves.

A person's ability to make decisions for themselves is called 'legal capacity'. The guardianship law uses the term 'protected person' to describe someone with 'impaired decision-making ability'. This impaired ability can be the result of the person having, for example, a disability, an injury or an illness.

Guardianship occurs when the ACT Civil and Administrative Tribunal (ACAT) decides that someone requires this protection. ACAT will then decide who would make decisions for the 'protected person'. ACAT will often choose a family member or carer, but if no one else is available or suitable it could be another trustworthy person or the public advocate.

When the chosen person has wide responsibilities for making decisions for someone, they are called a 'guardian'. When the person is appointed to make decisions in relation to money or property, the law calls them a 'manager'. When someone is appointed to make health care decisions, they are called a 'health attorney'.

These are all 'substitute decision-makers' – they make decisions about the protected person instead of the person making those decisions. The substitute decision-makers must comply with a set of decision-making principles under the Act. These principles aim to fulfil the wishes of the protected person to the greatest extent possible, without going against the protected person's interests. They also aim to maximise the protected person's independence, lifestyle and participation in the community, within the protective framework.

The principles mean that any person who is appointed as a substitute decision-maker under the ACT law must protect the interests of the protected person in any decision that they make for them. However, they must make decisions that are the least restrictive of the wishes of the protected person.
1. Tell us about your experiences with the current Guardianship arrangements in the ACT: what has worked for you and/or what problems you have had with them?
2. YOUR EXPERIENCE OF POWERS OF ATTORNEY

The guardianship law in the ACT is closely related to laws about 'enduring powers of attorney', made under the Powers of Attorney Act 2006.

A power of attorney is another form of substitute decision-making. It is a document, made by someone when their decision-making is not impaired, which appoints one or more people to make decisions for them if their decision-making ability becomes impaired in the future.

The person making the power of attorney is called the 'principal'. The person appointed to be a future decision-maker is the attorney.

A power of attorney can cover financial and property decisions, personal care decisions such as where someone lives, and health care decisions. The attorney must make decisions in accordance with these principles:

> the person has a right to respect for their human dignity and worth as an individual
> the person has a right to be a valued member of society and to perform social roles
> the person should be encouraged and supported to live and participate in the general community
> the person's need and wish for a reasonable quality of life is recognised and taken into account
> the person has a right to participate in decisions affecting them to the greatest extent possible, and
> the person has a right to access to family members and relatives, and to involve them in decision-making.

LRAC thinks that the experiences of people using powers of attorney may be useful in looking at the experiences of people using the guardianship legislation. It is also likely that any reform of the guardianship law will lead to changes in relation to powers of attorney.
2. Tell us about your experiences relating to powers of attorney: what has worked for you and/or what problems have you had with them?
3. PROPOSED NATIONAL DECISION-MAKING PRINCIPLES

On 13 December 2006, the United Nations (UN) adopted the Convention on the Rights of Persons with Disability, and Australia has been bound to comply with the Convention since August 2008. In the UN Convention, Article 12 states that:

- people with disabilities have the right to 'enjoy legal capacity on an equal basis with others in all aspects of life';
- countries who are bound by the UN Convention must 'take appropriate measures to provide access to persons with disabilities to the support they may require in exercising their legal capacity', and
- countries who are bound by the UN Convention must ensure that measures relating to the exercise of legal capacity:
  - respect a person's rights, will and preferences;
  - are free of conflict of interest and undue influence;
  - are proportional and tailored to the person's circumstances;
  - apply for as short a term as possible, and
  - are subject to regular, independent external review.

The Australian Law Reform Commission has examined the impact of the UN Convention on federal laws. The Commission's final report Equality, Capacity and Disability in Commonwealth Laws, and a summary of it, are available here:


The Australian Law Reform Commission recommends the approach of 'supported decision-making' the UN Convention, and that guardianship laws be consistent with four National Decision-Making Principles:

1. all adults have an equal right to make decisions that affect their lives and to have those decisions respected;
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. the will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives, and
4. there must be appropriate and effective safeguards for people who may require decision-making support, including to prevent abuse and undue influence.

The ACT is the first jurisdiction to consider implementing these National Decision-Making Principles.
3. What do you think about the National Decision-Making Principles proposed by the Australian Law Reform Commission? Are they the best way of designing a law that allows people to make decisions in a way consistent with the rights of people with disabilities under the UN Convention?
4. PROPOSED GUIDELINES FOR DECISION-MAKING SUPPORT

The Australian Law Reform Commission proposes Guidelines to help give effect to the four National Decision-making Principles. The first set of Guidelines helps give effect to the Principles that:

all adults have an equal right to make decisions that affect their lives and to have those decisions respected, and

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.

General guidelines

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.

Guidelines for 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.
4. What you think about the Australian Law Reform Commission's Guidelines for Decision-Making Support. Do you think they are useful? Is there anything else that should be there?
5. Proposed Guidelines for Giving Effect to Will, Preferences and Rights

The Australian Law Reform Commission proposes Guidelines to help give effect to each of the four National Decision-making Principles.

The second set of Guidelines helps give effect to the Principle that the will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

The Guidelines set out two tiers of decision-making support. The first is when a person is able to make a decision for themselves with the help of a 'supporter'. The second is when a person is not able to make a decision for themselves even with support, and requires a 'representative' to make the decision for them.

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.

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.
5.1. What do you think about the Australian Law Reform Commission's Guidelines for Giving Effect to Will, Preferences and Rights? Do you think they are useful? Is there anything else that should be there?

This sounds useful. I have nothing to add to it.
5.2. What evidence should a supporter be required to keep to show that they provided support to help the person make a decision? Should this vary with different types of decisions?

The person should keep a record. No, this shouldn't vary.

5.3. What evidence should a representative be required to keep about how they made a decision that gave effect to the person's will, preferences and rights? Should this vary with different types of decisions?

A person's record should be enough.

I think yes—depending on the decision and the person, e.g., a person with dementia compared with a person without dementia.
5.4. How will a representative work out what the person would likely want when the person is unconscious or otherwise unable to communicate their wishes and preferences? If the person could move a little bit they could give yes or no answers. You could know what a person wants and from generally knowing the person.

5.5. What if the people consulted by a representative do not agree about what the person would want? Should a representative’s decision be able to be challenged – how and by whom? A person’s representative should be able to be challenged. Perhaps by their parents if they are still around.
6. PROPOSED GUIDELINES FOR SAFEGUARDS

The Australian Law Reform Commission proposes Guidelines to help give effect to each of the four National Decision-making Principles.

The third set of Guidelines helps give effect to the Principle that there must be appropriate and effective safeguards for people who may require decision-making support, including to prevent abuse and undue influence.

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.

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.
6. What you think about the Australian Law Reform Commission's Guidelines for Safeguards. Do you think they are useful? Is there anything else that should be there?

The Guidelines can help keep control of you while you are live in an institution and once you get out you could regain control of your life. I think they are good. It should include talking to the family.
7. OTHER APPROACHES FOR SUPPORTED DECISION-MAKING

There are ways of providing support for decision-making that do not rely on the law, and many options have been proposed. The names and exact nature of these options vary (such as mini-boards, or circles of friends or peers).

For example, in the ACT, Advocacy for Inclusion has outlined a range of possible approaches, such as:

- support networks
- single supporters
- co-decision-making agreements
- representation agreements, where someone nominates a trusted person to help with specific decisions at specific times.

Most options recognise that support may be needed at different stages and in different areas of a person’s life, from recognising that a decision needs to be made, through gathering information, to making the decision and following it up.
7. What suggestions do you have for ways of providing decision-making support?

None.
8. WHEN AND HOW TO GIVE SUPPORT FOR DECISION-MAKING

Changing from substitute decision-making to supported decision-making would involve a lot of changes for everybody involved. Everybody would have to think and work differently: people with disabilities, families, carers, advocacy organisations, and government and private organisations.

People who are used to relying on the existing guardianship arrangements would need to think and act differently when, for example, someone signs a contract or makes decisions about their money. One of the challenges would be to respect a person's right to make their own decisions, even to make poor decisions.

There are, however, already many examples of people working with supported decision-making. Family members who are guardians often help a person to make their own decisions. Adult children acting as guardians for an elder parent talk through options for health and personal care with their parent to see what their preference is.

So, while a change to a supported decision-making legal framework would be a significant change in the law, it may not be too different for some families in practice.
8.1. How can a person's need for support be balanced with the person's right to independent decision-making?

By talking to me before making a decision.

However, I am able to communicate and many people cannot.
8.2. How can we know what level of support a person needs, and when they need it? By talking to doctors, to the person themselves. You could talk to staff, carers, families and friends.
9. Have you had any experience with supported decision-making? If so, tell us about what worked well and what didn't.

No.
10. STAGES IN SUPPORTED DECISION-MAKING

There have been a number of trials of supported decision-making in Australia and overseas. One result of an ACT trial was the production of a website to help people who require decision support and their families. The website, www.support-my-decision.org.au, was developed by the ACT Disability, Aged and Carer Advocacy Service (ADACAS).

Many of the trials of supported decision-making have involved people with intellectual disabilities becoming decision-makers. There have been fewer trials involving those who may need support because their decision-making ability is reduced by illness or frailty.

Often people with mental illness or older people have had the ability to make decisions without support, but they now need support. Their need for decision-making support may vary at different times.

The pilots suggest that several stages are necessary to help supported decision-making work:

1. First, it is necessary to raise the awareness of people with disabilities who have not had much current decision-making experience (called potential decision-makers here), and those who share their lives that the person has a right to make decisions.

2. Then, because making decisions is a learned skill, the next step is to help people to become ‘decision-ready’, by helping them understand decision ideas like options, risks, and to develop skills like how to approach a decision.

3. A supporter needs to be identified from available supporters, who could be from a trusted group of friends, peers and family, or be a specific trusted person (including a family or paid carer) or an organisation.

4. The supporter needs to work out the person’s wishes in relation to the decisions they want to be involved in and what sort of support is needed.

5. The potential decision-maker and the supporter have to work out how to work together, so that the potential decision-maker’s own capacity to make independent decisions is improved.

6. Finally, the decision is made and then carried out, with support as necessary to also monitor and review the decision and its impact.
10. Trials of supported decision-making have identified stages in the process of supported decision-making. Do you have any comment about how these stages might work in practice?

No.
11. ISSUES RAISED BY SUPPORTED DECISION-MAKING

The results of the trials of supported decision-making have generally been positive for the participants and their families. Some of the issues which have arisen include:

> supporters and representatives need training in their new roles, and to understand the fundamental differences between guardianship and supported decision-making

> family members fear that, if someone who needs support in making decisions can choose not to use support at any time and is making their own decisions, they will be exploited or 'ripped off' by unscrupulous people, sometimes posing as friends

> there is a risk from unsolicited marketing, for example, mobile phone companies and insurance companies, who call people at home and try to enrol them in contracts over the phone; if everyone is assumed to have legal capacity, how can people's financial position be adequately safeguarded?

> it is not always obvious to someone that the person they are dealing with has memory or perception problems which can interfere with their ability to make decisions; how will someone know the person needs support in making a decision?

> people with disabilities need training to provide them with the skills necessary to make decisions, and sometimes the need to 'practise' in a safe way before becoming fully responsible for their own decision-making

> there is a risk of over-regulation of support processes which may put an added burden on the relationships between people with disabilities and their carer/family

> there is a lack of resources and time to assess the needs of someone for support in decision-making and then to provide adequate support.
11. Trials of supported decision-making have raised some issues about how supported decision-making works in practice, such as training and skills, risk of exploitation, timing of support, burdensome regulation, and lack of resources. Tell us what you think about these issues.

Yes, it could be useful.
12. OTHER AREAS FOR REFORM

A change from substitute decision-making to supported decision-making has wide implications for the law, underpinned by a recognition of all people having a right to autonomy and a right to make their own decisions. This has implications for areas of law other than guardianship, such as:

> voting
> marriage and parenting
> capacity to be a witness, to be a juror and to take legal actions
> employment arrangements
> being a board member or holding official positions
> fitness to plead in criminal matters.
12. What areas of life do you think will be affected by such a commitment to a person's autonomy, and right to make their own decisions, and what changes should be made to decision-making in these areas of life?

I could do all of these things but someone with dementia couldn't.
Thank you for telling us what you think!