



Office of the Public Advocate

# Supported decision-making

## Background and discussion paper

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## **Contents**

<b>1. Introduction.....</b>	<b>3</b>
<b>2. Background .....</b>	<b>3</b>
<b>3. Definitions.....</b>	<b>4</b>
3.1 Capacity, legal capacity and competence .....	4
3.1.1 Legal capacity: .....	4
3.1.2 Capacity .....	5
3.1.3 Competent / incompetent .....	5
3.2 Decision-making .....	5
3.3 Supported decision-making .....	8
3.4 Substitute decision-making .....	10
<b>4. The United Nations Convention on the Rights of Persons with Disabilities.....</b>	<b>11</b>
<b>5. Supported decision-making in overseas law, policy and practice .....</b>	<b>12</b>
5.1 Canada.....	13
5.2 The United Kingdom .....	14
5.3 Sweden.....	15
<b>6. The continuum of supported and substitute decision-making.....</b>	<b>15</b>
6.1 Forms of supported and substitute decision-making. ....	15
6.2 Supported decision-making in guardianship and administration? .....	17
<b>7. Towards an Australian model of supported decision-making.....</b>	<b>20</b>
7.1 Proposed scope.....	20
7.2 Suggested Principles .....	20
7.3 Possible framework and forms.....	21
7.4 Possible safeguards .....	22
<b>8. Key Issues and discussion.....</b>	<b>23</b>



# 1. Introduction

A major responsibility of the Public Advocate under the Guardianship and Administration Act 1986 is to promote the development of the ability and capacity of persons with a disability to act independently.<sup>1</sup>

The United Nations Convention on the Rights of Persons with Disabilities 2006 and the Victorian Charter of Human Rights and Responsibilities 2006 have brought into sharp focus the questions around supporting people with disabilities to make decisions about their lives.

The current review of the Guardianship and Administration Act 1986 by the Victorian Law Reform Commission has, amongst its terms of reference:

- the consideration of developments in policy and practice in respect of persons with impaired decision-making since the Act commenced;
- the role of guardians and administrators in advancing the represented person's rights and interests and in assisting them to make decisions.

This discussion paper aims to explore questions and issues around supported decision-making, to promote discussion in the field and to consider how supported decision-making should be incorporated into Victorian policy and/or legislation.

Guardianship in Australia has, under the Guardianship and Administration Act 1986, been conceptualised as a last resort with a guardian appointed only when less restrictive options have failed or are not available. For guardianship to properly be a last resort, there must be an adequate first resort. The United Nations Convention establishes supported decision-making as the first resort: the preferred alternative and, where necessary, precursor to guardianship.

The paper intentionally does not engage with the debate about whether guardianship is permissible under Article 12 of the United Nations Convention on the Rights of Persons with Disabilities. It proceeds on the basis that guardianship (substitute decision-making) continues to be legitimate with appropriate safeguards.

## 2. Background

Supported decision-making is based on the principles and theory of normalisation.

Most people in the community seek the support of others in making significant decisions about their lives. In modern society there is a high level of dependence on the expertise and knowledge of those with special qualifications, skill and talents depending on the sorts of decisions that a person is faced with. In addition, people talk about their choices with others and few decisions, especially about important matters, are made in isolation. In our society, relying

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<sup>1</sup> *Guardianship and Administration Act 1986* (s15(a)(i))



on the advice of others is not seen as an indication that a person lacks the mental capacity to make his or her own decisions.

It is therefore argued that the idea of the independent, autonomous decision-maker, at least as far as the process of decision-making is concerned, is a myth and that *interdependent* decision-making is the way in which most of us operate. The amount of support and assistance people seek and receive to make decisions varies, depending on the person's ability, personality and life circumstances and on the particular decision. Some people need more assistance and support than others do.

Over the past ten or twenty years, disability groups in Australia and elsewhere have recognised this and suggested that formal support networks for people with disabilities would enable them to make normal life decisions with the support of family, friends and service providers thus fostering their independence and reducing the need for guardians to be appointed.

There are some supported decision-making arrangements currently existing in Victoria within services and advocacy organisations for people with disabilities but they are not widespread. They are generally used for decisions that do not involve a legal contract or obligation and where there is no significant risk of harm or detriment to the person with a disability. The overwhelming majority of decisions a person with a disability makes are like this.

Under our current legal framework, these forms of supported decision-making are not available for people who lack the capacity to understand the legal nature and effect of the particular decision. However, the terms of reference of the Victorian Law Reform Commission for the review of the Act include consideration of:

“the role of guardians and administrators in advancing the represented person's rights and interests **and in assisting them to make decisions**” (emphasis added).

An unfortunate aspect of the current discussion about supported decision-making, in Australia as well as overseas, has been the denigration and criticism of guardianship that has frequently accompanied it, even in United Nations CRPD publications. Whilst serious accusations of human rights abuse can be levelled against guardianship in some countries, this is not generally the case in Australia.

## 3. Definitions

### 3.1 Capacity, legal capacity and competence

The use of these terms and the definitions given to them is creating considerable confusion in discussions of supported decision-making.

#### 3.1.1 Legal capacity:

In legislation, the term legal capacity usually means that a person has sufficient knowledge and understanding to reach the threshold of capacity necessary to commit to a legal contract or take legal action on his or her own behalf. The phrase “understand the nature and intent of the document” or similar is widely used.

The United Nations Convention on the Rights of Persons with Disabilities, Article 12(2) states:



States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

Used in this way legal capacity describes the rights and status of a person and is not connected with cognitive competence. Although legal capacity is not defined in the Convention, the Parliamentarians Implementation Handbook suggests that legal capacity refers to rights such as the right to vote, hold property and take legal action that in many countries can be automatically removed when a person has a disability<sup>2</sup>. It needs to be understood together with Article 12(1) that affirms that people with disabilities have the right everywhere to recognition as persons before the law – that is, they have legal personhood. There is at present emerging debate about whether the defence of mental impairment in criminal law is consistent with Article 12(2), with one view being that this defence should be abolished and replaced by the application of “disability-neutral doctrines on the subjective element of the crime ... which take into consideration the situation of the individual defendant”<sup>3</sup>.

### **3.1.2 Capacity**

Capacity is frequently used in medicine, law and disability as a statement of whether a person has sufficient understanding to make valid decisions about the matter at hand. In medicine, this is generally about consent to medical treatment. It is preferred to the term competence because capacity is usually framed as being decision-specific and context specific. Capacity is an ability and comes in degrees. A person may have the capacity to make decisions in some circumstances or about some matters but not others. The United Nations Convention refers only to “legal capacity”, not to “capacity”. The Convention 12(3) speaks of “support in exercising legal capacity” and arguably article 12(4) frames guardianship (without actually using the word) as “measures relating to the exercise of legal capacity”.

### **3.1.3 Competent / incompetent**

Competent is a characteristic of a person and is an “all or nothing” concept attached to that person. A person is either competent or incompetent. The term is often used interchangeably with capacity/incapacity but is less used in recent years for this reason. The Convention does not use the terms competent and incompetent.

The Guardianship and Administration Act does not refer to competence or capacity. The standard for the appointment of a guardian is that the person with a disability must be “unable by reason of the disability to make reasonable judgments in respect of all or any of the matters relating to her or his personal circumstances”. Those working in the guardianship field however generally refer to the three-tier test for the appointment of a guardian under the Act as “disability, capacity and need”.

## **3.2 Decision-making**

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<sup>2</sup> [www.un.org/disabilities/default.asp?id=242](http://www.un.org/disabilities/default.asp?id=242)

<sup>3</sup> Annual Report of the United Nations High Commissioner for Human Rights and Reports of the Office of the High Commissioner and the Secretary General: Thematic Study of the United Nations High Commissioner for human rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities. A/HRC/10/48, Paragraph 47



Before looking more closely at supported decision-making, it is important to look at decision-making itself, in particular at the elements involved. There are many decision-making models to draw upon but much of the thinking about decision-making in the disability area has been done in connection with medical consent. The analysis of decision-making takes place in the context of assessing whether a person has sufficient capacity to provide valid consent to a medical procedure.

The *Stanford Encyclopaedia of Philosophy*<sup>4</sup> contains the following entry by Louis Charland on decision-making capacity in the medical context:

Decisional capacity may be divided into four sub-capacities. These are: (1) Understanding; (2) Appreciation; (3) Reasoning; (4) Choice. In some instances, capacity is also said to include: (5) Values. But not always. The basic elements of capacity and their rationale are the following:

(1). Understanding. Perhaps the most basic element of capacity is understanding. Obviously, in order to be capable of consenting to or refusing a given treatment, a subject must have some basic understanding of the facts involved in that decision. Yet this apparently simple requirement can turn out to be rather complex depending on how ‘understanding’ itself is defined. Basic comprehension and knowledge or cognition of facts is one minimal interpretation. However, most commentators recognize that this level of mental ability is not enough for generating the sort of health care decisions we are concerned with.

(2). Appreciation. In addition to understanding in the basic factual sense alluded to above, most writers on capacity agree that subjects must also have some appreciation of the nature and significance of the decision that they are faced with. The reason is that in order to understand what the facts in a decision really ‘are’, they must mean something to the decision-maker. Very basically, subjects must recognize that this really is their decision to make, that it is their life and values and future that are at stake. Thus, in addition to understanding, subjects must be able ‘to appreciate the nature and meaning of potential alternatives — what it would be like and “feel” like to be in possible future states and to undergo various experiences — and to integrate this appreciation into one’s decision making’. This element of capacity is sometimes held to derive from the legal requirement that each subject must have ‘insight’ into the circumstances of a given decision.

(3). Reasoning. Without the mental ability to engage in reasoning and manipulate information rationally, it is impossible for understanding and appreciation to issue in a decision. The concept of reasoning is often left vague in discussions of decisional capacity. Probably this is because insisting on too high and specific a normative standard of reasoning might risk making a majority of health care subjects decisionally incapable; a *reductio ad absurdum* of any theory of decisional capacity that implied such a result. Yet normative standards of reasoning sometimes do get mentioned, for example, consistency and the ability to derive conclusions from premises. Reasoning is also usually said to include the ability to weigh risks and benefits and evaluate

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<sup>4</sup> <http://plato.stanford.edu/entries/decision-capacity>



putative consequences. Again, no specific normative criteria for success are spelled out. Difficult cases must therefore be assessed individually.

(4). Choice. It is possible to imagine a case where understanding and appreciation and reasoning are all intact, but where a subject has no way to express or communicate their intended decision. It is impossible for them to express a choice. Yet unless a subject's preferred choice can be expressed to others in some outward way, it is impossible to know their intended decision. The condition is not trivial, since some patients — for example, stroke victims — can have an active mental life and satisfy our first three conditions for capacity, but are unable to express anything verbally or through gestures (e.g. blinking the eyes, lifting a finger etc.). This has led some commentators to add the ability to express a choice to the list of elements that comprise capacity. This is perhaps the least mental of the sub-capacities that constitute capacity, which may explain why it is not considered an element of capacity by some authors.

(5). Values. In addition to these four elements of capacity, some theorists explicitly state that capacity requires a set of values. Since a subject's values can be expected to change over time, what is required is not an immutable, fixed, set of values, but a minimally consistent and stable set of values. Another way of expressing this point is to say that capacity requires 'a conception of what is good'. The reason for this last requirement should be obvious. Weighing the risks and benefits of various alternative choices requires values. So does selecting one option over others. Yet some leading accounts of capacity are strangely silent over the role and place of values in capacity. Perhaps this is because the formulation and elaboration of values to guide choice usually involves emotion. As we will see, this is an aspect of capacity that some theorists would prefer to downplay.

Louis Charland, later in the same entry, discusses emotion as another necessary element of decision-making.

Leading clinical theories and tests of decisional capacity tend to be exclusively cognitive in nature and orientation. As a result, those tests and theories ignore the positive contribution of emotion to capacity. Of course, emotions and their associated feelings can conflict with and impair the mental functions that underlie capacity. But what is rarely acknowledged is that emotions and feelings also have a positive role to play; indeed, that capacity without emotion is impossible.

Philosophers have been stressing the positive importance of emotion for the theory of decisional capacity for some time. After all, it seems obvious that most decisions to consent to or refuse treatment are made largely on the basis of emotion, or at least have important contributing emotional factors. Thus, there is the hope or despair that one will get well; or there can be anger, fear, or joy that one will undergo a given procedure. In such cases emotions and their underlying valuations often function as reasons for action. Not surprisingly, concerns over the absence of emotion from leading models of capacity have started to emerge in the clinical literature on capacity. Here it is important not to forget that decisional capacity in the context of consent is invariably a matter of 'practical judgment'. This makes the contribution of emotion doubly important. The reason is that in practical judgment emotions are 'on-line' and therefore usually have a marked felt bodily dimension.



Emotions and their associated feelings both embody and promote core values of the organism. Thus an important corollary of the fact that emotions are central to decisional capacity, is that values as well are equally important. Yet most leading theories of capacity have very little to say about value, preferring instead to stick to ostensibly more tangible and 'objective' matters of fact. As a result, subjects are seldom asked 'why' questions that probe into the values behind their expressed preferences. Yet in the case of mental disorders that impair valuation, there are good reasons to think this information highly clinically relevant. Indeed, pathologically-induced changes in values appear to play a large role in a number of medical conditions where capacity is thought to be impaired.

### 3.3 Supported decision-making

Supported decision-making is presently quite loosely defined and articulated and there is very little material in literature or policy to draw upon. The United Nations Handbook on the Convention states:

Supported decision-making can take many forms. Those assisting a person may communicate the individual's intentions to others or help him/her understand the choices at hand. They may help others to realize that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/her legal capacity.

While some good models of support networks exist, there is generally no clear policy framework; guardianship laws and practice still dominate. It is sometimes difficult to designate support networks, particularly when an individual cannot identify a trusted person or people. In addition, people in institutional settings are often denied support, even when it is available. Establishing comprehensive support networks requires effort and financial commitment, although existing models of guardianship can be equally costly. Supported decision-making should thus be seen as a redistribution of existing resources, not an additional expense.<sup>5</sup>

The Mental Disability Advocacy Council, the influential human rights organization that has done extensive work on guardianship and human rights in Europe, defines supported decision-making thus:

This alternative to guardianship is premised on the fact that with proper support, a person who would otherwise be deemed to lack capacity is, in fact, able to make personal decisions.

The literature is vague on the questions around capacity, such questions tending to be dismissed as reflective of the old paradigm. Questions about capacity may also generate more disagreement than other issues and so there may be a preference to concentrate on the positives and agreed territory of supported decision-making rather than the points of difference. However, the importance of coming to some agreement has been recognised by the United Nations with the Annual day of General Discussion on 21 October 2009 being devoted to Article 12 of the Convention.<sup>6</sup>

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<sup>5</sup> <http://www.un.org/disabilities/default.asp?id=242>

<sup>6</sup> Papers submitted for this meeting may be found at:  
<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGD21102009.aspx>



The following is drawn mainly from the writing and presentations of people in the intellectual and psycho-social disability area, much of which is reflected in the United Nations Handbook on the Convention.

Supported decision-making is a framework within which a person with a disability can be assisted to make valid decisions. The key concepts are empowerment, choice and control. Responsibility, including legal responsibility, is another essential aspect that needs to be considered.

The premise of supported decision-making, as articulated by the disability community, is that everyone has the right to make their own decisions and to receive whatever support they require to do so. The basic premise (that everyone has a right to make their own decisions) is squarely within the Western philosophical tradition of autonomy and self-determination and does not present any challenge to this paradigm. The second part of the premise, receiving support to do so, raises the question of whether this is consistent with autonomous decision-making. Tina Minkowitz argues that interdependence and autonomy can co-exist and already do so in reality through the normal processes of decision-making.<sup>7</sup>

Supported decision-making was first developed for people with intellectual and communication disabilities. Some of the principles identified as underlying supported decision-making are:

- People are capable of making decisions about most areas of their lives.
- Everyone has a will and can communicate their will and preferences. These preferences can be built into valid decisions.
- The person should receive whatever support they need and wish to receive in order to make decisions.
- Competency can be learned, influenced, enhanced and suppressed.
- The person makes and retains control over the decisions made and takes responsibility for them.
- People have the right to take risks in their lives.
- People do not always make good decisions but can learn from their mistakes and experience.
- Supported decision-making must involve the full agreement of the person and his/her supporters.
- Support should be independent of service delivery.<sup>8</sup>

The classic model of support identified within the disability community involves:

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<sup>7</sup> Minkowitz, T: The Paradigm of Supported Decision Making. (Powerpoint presentation) at [www.barcsi.hu](http://www.barcsi.hu)

<sup>8</sup> These principles have been put together from a range of sources including a presentation by Tina Minkowitz. A strongly worded set of legal principles based upon the UN Convention has been developed in a presentation by Michael Bach: Supported Decision-making – Lessons from Canada, May 2007. [www.inclusion-europe.org/documents/EiA07-Bach.pdf](http://www.inclusion-europe.org/documents/EiA07-Bach.pdf)



- A long-term relationship of trust with one or more individuals.
- Unpaid support, usually drawn from friends, family, community.
- Flexibility to respond to varying needs at different times.
- Agreement by all involved to support the person in reaching and expressing his/her decisions.
- Agreement about which types of decisions will be made through supported decision-making.
- Provision of information and explanations in plain language.

Supported decision-making may also involve a written agreement between designated support people, written plans and documented decisions. The closest example in the Australian context to classic supported decision-making is probably the Citizen Advocacy model.

In Victoria, work on supported decision-making has been undertaken by Jo Watson from Scope Victoria over a number of years<sup>9</sup>. Her work is particularly valuable, in that it explores the nature of the assistance that can be provided as well as the framework and paradigm. The Department of Human Services, Victoria is also developing a model of supported decision-making for use within its services.

### **3.4 Substitute decision-making**

Guardianship is the most common form of substitute decision-making, although Enduring Powers of Attorney are another form. Most countries have a form of legal guardianship whereby another person or organisation is appointed to make financial, legal and/or personal decisions for a person who is unable to make decisions for him/herself.

In countries such as Australia that have modern guardianship systems, the values and principles of guardianship and supported decision-making are similar, if not the same. Promoting and protecting the rights, dignity, interests and wellbeing of the person are paramount. The person is central, they are fully consulted and their wishes are given effect to wherever possible. Civil and political rights are not removed under guardianship, orders are limited in scope, less restrictive means of addressing issues must be considered, orders may be appealed and are regularly reviewed. Guardians must act in the interests of the person with a disability and are held to account for the decisions they make.

In some countries, however, a person's civil and political rights are automatically removed when they are placed under guardianship. The right to hold property, to vote, to work, to take a matter to Court, to marry or stand for public office are some of the rights that may be removed. Review of guardianship, accountability of the guardian, the right of appeal and safeguards requiring the guardian to act in the interests of the person are absent in some countries. Over the past ten years, the work of the Mental Disability Advocacy Centre in Budapest has exposed

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<sup>9</sup> Watson, J: Decision-making and choice for people with high support needs: a way forward?  
[www.cpaustralia.com.au/news/watson.pdf](http://www.cpaustralia.com.au/news/watson.pdf)



such practices in many Eastern European countries. These systems and practices, and the drive to abolish them, were very influential in the framing of the Convention.<sup>10</sup>

Whilst guardianship systems vary greatly across the world, they can all be distinguished from supported decision-making by the fact that the guardian, rather than the person, ultimately makes the decisions and takes responsibility for them. This concept of responsibility meshes with the concept of diminished responsibility in the common law.

## 4. The United Nations Convention on the Rights of Persons with Disabilities

Much of the current discussion of supported decision-making has arisen from the United Nations Convention on the Rights of Persons with Disabilities 2006. This Convention is the first UN Convention negotiated with the civil society (groups and organisations) rather than just between States.

Supported decision-making is referred to briefly in the Convention in Article 12 on Equal Recognition before the Law. Article 12(3) provides that States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

### Article 12: Equal Recognition before the Law

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 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

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<sup>10</sup> To follow up the work of MDAC see [www.mdac.org](http://www.mdac.org)



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.

During the Convention negotiations, the psycho-social disability groups promoted the view that capacity is socially constructed and has historically been used to exclude marginalised groups such as women. They also argued that the legal construction of capacity privileges cognitive capabilities, thus manufacturing incapacity in those who make decisions on an emotive or intuitive basis and failing to recognise different and equally valid ways of being human.<sup>11</sup> The proposed solution, which was adopted in the Convention, was that the Convention should state unequivocally that all persons with disabilities have legal capacity and may receive support to exercise that capacity.<sup>12</sup> The corollary of this position, that all decision-making of people with disabilities should be in the supported decision-making framework with no provision for substitute decision-making, was not fully adopted, notwithstanding that the wording of the Convention refers to “measures relating to the exercise of legal capacity” rather than substitute decision-making.

## 5. Supported decision-making in overseas law, policy and practice

Prior to the UN CRPD, supported decision-making was found mainly in Canada where it has been incorporated into policy and, to a limited extent, legislation over the past ten years. In Canada, it is termed assisted decision-making.

Professor Robert Gordon, a prominent Canadian academic in the field, has articulated three forms of supported decision making:<sup>13 14</sup>

- Assisted Decision-Making as a specific Court-ordered alternative.

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<sup>11</sup> See Dhanda, Amita: Advocacy note on legal capacity at <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGD21102009.aspx> This is different from the Note of the same title referred to in footnote 10

<sup>12</sup> Dhanda, Amita: Advocacy note on legal capacity. United Nations 2003-2004. [www.un.org/esa/socdev/enable/rights/art9legal.htm](http://www.un.org/esa/socdev/enable/rights/art9legal.htm)

<sup>13</sup> Gordon, Robert: The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making. *International Journal of Law and Psychiatry* Vol 23 (1) 2000.

<sup>14</sup> Robert Gordon is also a member of the Reference Group of the Victorian Law Reform Commission's Review of the Guardianship and Administration Act 1986.



- Assisted Decision making as a specifically identified and defined alternative to Court-ordered Guardianship.
- Assisted Decision-Making as an indirectly identified and undefined alternative.

## 5.1 Canada

Canada has a range of formalised and semi-formalised supported decision-making arrangements. These vary according to the guardianship law in the particular province and to whether legislation makes reference to supported (assisted) decision-making. In some provinces, supported decision-making is based in policy rather than in legislation. A few examples indicate the ways in which supported decision-making has been put into practice in Canada.

Plan Canada is a community organization established in British Columbia with affiliate organisations in Alberta, Saskatchewan, and Ontario. It was founded by families of people with disabilities to assist them to have a good life today and to plan for the future so that appropriate services and support networks are in place. In British Columbia, Plan assists people to set up Representation Agreements.

The Canadian Association for Community Living, established in 1958, is a national association of over 40,000 individuals, 400 associations and 13 Provincial Associations for Community Living. It is committed to supporting people with disabilities to live independently in the community. CACL is undertaking an extensive project on supported decision-making and legal capacity in conjunction with People First of Canada and the ARCH Disability Law Centre that will develop information tools for people with intellectual disabilities in these areas.<sup>15</sup>

Under 2005 Yukon legislation, a person may make a Supported Decision making Agreement under the *Adult Decision Making and Protection Act* Part 1. This is an agreement between two or more adults to formalise a support relationship and allows the adult to authorise an Associate to help them make decisions in any or all areas. The adult must be able to understand the nature and effect of the agreement and the agreement ends when the person loses capacity. There is a prescribed form that allows the adult to state what areas are covered in the agreement, who the associates are and other relevant matters. The associate is not permitted to make decisions for the person with a disability. The legislation also allows for Representation Agreements which also cease if a person becomes incapacitated and Enduring Powers of Attorney for financial matters.

In British Columbia a person may enter a Representation Agreement with a Support Network. The representation agreement is a sign to others such as doctors, financial organizations and service providers that the person has give the network the authority to assist him or her in making decisions and to represent him /her in some matters.<sup>16</sup> There are two levels of agreement. Under a Section 7 agreement, a person can enter an agreement on the basis that s/he is over 19 years of age and can demonstrate trust in the supporters rather than having to meet the more usual criteria of competence and understanding. A Section 7 agreement covers lower levels of responsibility. If a person has capacity, s/he can grant additional powers under a

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<sup>15</sup> See website at [www.cacl.ca](http://www.cacl.ca)

<sup>16</sup> From provision to practice: implementing the Convention. UN Enable Chapter 6. [www.un.org/disabilities/default.asp?id=242](http://www.un.org/disabilities/default.asp?id=242)



Section 9 agreement. This can cover areas such as taking a person to hospital against their will (the Ulysses agreement) and decisions about complex medical treatment. A Section 9 agreement must be made in conjunction with a lawyer. A community-based legal organisation, Nidus (formerly the Representation Agreement Resource Centre), assists people to set up support networks and make Representation Agreements. It also runs a registry on which the Representation Agreement can be posted. Posting the Representation Agreement on the registry is not an essential part of the agreement. Access to the registry is restricted to those named by the person making the agreement. There is a one-off cost of \$25 to post the agreement on the database. In contrast, the cost of making a guardianship application is \$3,000 to \$5,000.<sup>17</sup>

In Alberta, the Adult Guardianship and Trusteeship Act 2008 that came into force on 30 October 2009, provides for supported decision-making authorisations and co-decision making orders.<sup>18</sup> Supported decision-making authorisations allow a person with capacity to nominate another person to assist them to make and implement personal decisions. Co-decision making orders allow the Court, with the consent of the person, to appoint a co-decision maker for a person who could make decisions with support. The co-decision maker co-signs any personal decisions involving a contract. In both cases, the responsibility for the decisions remains with the person and the supporter or co-decision maker is absolved of legal responsibility if they have acted in good faith.

## 5.2 The United Kingdom

Work on supported decision-making in the UK is more recent. Much has been done in connection with the implementation of the *Mental Capacity Act* 2005 that came into force in 2007 in England and Wales.<sup>19</sup> A comprehensive discussion of capacity as it relates to supported decision-making under the UK Act may be found in the Queensland Law Reform Commission's recent discussion paper on principles and capacity in Queensland's guardianship legislation.<sup>20</sup>

The *Mental Capacity Act* 2005 provides a legal framework for the care, treatment or support for people who are unable to make some or all decisions for themselves. It sets out a process and principles for making decisions on behalf of others. A Court of Protection may appoint a deputy for a person unable to make their own decisions. Deputies are similar to guardians but there is no statutory guardian of last resort or provision for guardians to be paid from the public purse. Instead, the Act provides for Independent Mental Capacity Advocates for people who do not have family or friends and are facing serious life or health decisions. These advocates are based in community organisations.

Paradigm is a non-government organization that promotes supported decision-making for people with disabilities. In 2008, it published *Supported Decision-making: A guide for supporters*. The guide provides a good introduction to decision-making in accordance with the Act.<sup>21</sup> The UK is interesting in that it has taken a different path from other countries in this

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<sup>17</sup> Full information on Representation Agreements is provided on the Nidus website: [www.nidus.ca](http://www.nidus.ca)

<sup>18</sup> A useful website on Alberta Guardianship Law is [www.seniors.alberta.ca/services.../guardianship](http://www.seniors.alberta.ca/services.../guardianship)

<sup>19</sup> A useful website on the Mental Capacity Act is <http://www.publicguardian.gov.uk/mca/mca.htm>.

<sup>20</sup> Queensland Law Reform Commission: Shaping Queensland's guardianship legislation: principles and capacity. September 2008. 110-115.

<sup>21</sup> Paradigm: Supported Decision Making: a Guide for Supporters 2008 at [www.paradigm-uk.org](http://www.paradigm-uk.org).



area. It largely invests decision-making for those who are unable to make their own decisions in family, friends and professionals with legislated safeguards.

The Department of Health has also published a comprehensive guide to supported decision-making for introduction in social and residential care settings in the UK.<sup>22</sup> The guide is based on the requirements of the *Mental Capacity Act 2005*.

## 5.3 Sweden

Sweden has instituted a range of legal supports for people with disabilities.<sup>23</sup> The preferred form is mentorship. The civil rights of the person remain intact and the mentor acts only with the consent of the person. Mentors are appointed by a court and paid by the state and application for a mentor can be made by the person, a relative or the public trustees.

Where mentorship is inadequate because of the person's disability or circumstances, an administrator or trustee can be appointed to make substitute decisions to protect the person.

From within the welfare system, Sweden also provides for "contact persons", "personal assistants" and "escort persons", all paid by the public purse.

# 6. The continuum of supported and substitute decision-making

## 6.1 Forms of supported and substitute decision-making.

Supported and substitute-decision-making should be seen as a continuum with the decision-making that best reflects usual decision-making processes in our society at one end and fully substituted decision-making at the other.<sup>24</sup> Along the continuum, various models can be identified. The distinction drawn between supported decision-making and substitute decision-making along this continuum has been largely based upon where responsibility for the decision lies. In 1, 2, 4 and 5 the responsibility lies with the person/individual. In 6 and 7, it lies with another person than the one about whom the decision is being made. The exception is 3, in which the responsibility is shared by all members of the group. It is included at this point in the continuum because the process of decision-making is very similar to the classic model of supported decision-making.

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<sup>22</sup> Department of Health : *Independence, choice and risk: a guide to best practice in supported decision making*. May 2007.

<sup>23</sup> Nussbaum, Martha: *Frontiers of Justice: Disability, Nationality and Species Membership*. Harvard University Press. 2007: 196.

<sup>24</sup> Some disability advocates do not accept that substitute decision-making should be on the continuum because they see it as inconsistent with the paradigm of supported decision-making.



### Forms of supported decision-making

1. Supported decision-making may be completely informal, replicating the normal decision-making most people engage in and drawing on those whom the person trusts to assist them, usually family and friends. It has no legal or policy standing, except insofar as a service organisation or Tribunal may consider it in deciding the level of services a person needs or whether the person needs a guardian.
  
2. The classic model of supported decision making involves a long-term relationship of trust between a person with a disability and one or more other individuals, usually drawn from family, friends and community. There is flexibility to respond to varying needs at different times and agreement about the types of decisions to be made. It may involve a written agreement between the members of the group, written plans and documented decisions but this is not an essential feature.
  
3. “Competent decision making” is a form of group decision making in which the emphasis is placed on the competence, validity or integrity of the decision and the decision making process rather than the competence or capacity of the person to make the decision himself or herself. Legally the group takes responsibility for the decisions that are made. This form of decision-making has not been introduced in a systematic way in any country. There are isolated instances of a support group becoming incorporated under the Corporations Act.
  
4. Formalised Representation Agreements and support networks may be provided for in legislation and policy. In Canada, a person may make a Representation Agreement giving authority to their named support network to assist them in making designated decisions and this authority is recognised in law. Arrangements vary according to the law in each province. In British Columbia a person may give lower levels of authority on the basis of trust. Higher levels of authority require the person to understand the nature and intent of the agreement. Some provinces have a prescribed form for such an agreement. There is no provision currently for this type of agreement in Australia although Enduring Powers of Attorney could be re-framed to emphasise supported decision-making where possible.
  
5. Assistant or associate decision-makers may be appointed by a Tribunal or Court for a person who does not require a guardian if, with appropriate support, they could be assisted to make their own decisions. This is provided for in some Scandinavian countries and some Canadian provinces. The person with a disability retains their decision-making authority but there is some accountability of the assistant decision makers to the Court or Tribunal. There is no provision for this in Australia currently although the Office of the Public Advocate in Victoria can arguably provide a form of supported decision-making under its statutory advocacy function.

### Substitute or surrogate decision-making



6. Many of the principles of supported decision-making can be incorporated into guardianship legislation. This is recognised in the United Nations Convention in Article 12(4) that states:

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.

Australia signed the Convention on 30 March 2007 and ratified it on 17 July 2008. With the ratification, Australia entered a Declaration on the issues of substitute decision making, mental disability and immigration. The paragraph on substitute decision making states that Australia understands that the Convention allows for fully supported or substitute decision-making as a last resort and subject to safeguards.

Guardianship may be either plenary or limited (full or partial). Obviously plenary guardianship is more restrictive than limited guardianship and thus further along the continuum. Within both limited and plenary guardianship, decision-making may take two main forms:

6(a) Decisions based in substituted judgment. The decisions made are those that the guardian, after careful investigation and consideration, believes that the person would make if s/he was capable of doing so. It is most appropriately used when a person has previously had capacity to make their own decisions.

6(b) Decisions based on interests or best interests. In this form of decision making the wishes, well-being, risks and interests of the person are balanced and a decision made that is considered to be in the best interests of the person whilst being the least restrictive as possible of their freedom of decision and action.

7. Enduring Powers of Attorney. These allow a person to appoint a substitute decision-maker if s/he becomes incapable of making decisions in the future. In Victoria, a person can appoint an attorney under the Instruments Act to make financial decisions, an agent under the Medical Treatment Act to make medical decisions and an Enduring Guardian under the Guardianship and Administration Act. The legislative principles vary but neither the *Instruments Act* nor the *Medical Treatment Act* provide for the direct involvement of the donor in the decision-making. In addition, an Enduring Power of Attorney sets up a permanent, non-reviewed arrangement unless action to revoke or vary it is initiated by the person or the Tribunal. For these reasons, it has been placed at the end of the continuum.

## 6.2 Supported decision-making in guardianship and administration?



The question of whether supported decision-making can be incorporated within guardianship and administration is under active consideration in the review of the Guardianship and Administration Act.

Since the ratifying by Australia of the Convention, there has been a great deal of discussion about whether guardianship can be re-framed as supported decision-making. One viewpoint is that a guardian who takes account of a person's expressed wishes, respects their values and seeks to make the decision that the person would have made himself or herself is actually supporting the person to make their own decision. The alternative view is that such an approach is simply good substitute decision-making or guardianship, reflective of the shared values of supported decision-making and guardianship. The answer would appear to lie in where responsibility for the decision lies. Within guardianship, under current legislation, the responsibility for the decision unequivocally lies with the guardian.

A form of supported decision-making within guardianship that may fruitfully be explored would be for the guardian to have a role, specified in the legislation, in assisting a represented person to make decisions that are outside the terms of the guardianship order. Thus a guardian with authority limited to accommodation could have a role in supporting the represented person to make decisions about other areas of their life. This would be consistent with a guardian's responsibility to act as an advocate for the person. It would be important that there was clarity on whether the guardian was acting as a substitute decision maker or whether they were supporting the person to make their own decision.

Another question to be explored is whether a guardian appointed to make decisions in a general area of a person's life should support the person to make the decisions that they have the capacity to make within that area. An example would be a healthcare order. If a healthcare order was made in a situation where the presenting issue was a serious medical condition, the person may still be capable of making decisions about other less significant medical issues. Whilst it would seem preferable in these circumstances for a Tribunal to make an order that specified the serious medical condition as the area of guardianship, the alternative of the person retaining decision-making in the less significant aspects could be explored further. The issues that need to be clarified are how it should be decided which decisions the person can make, whether this should be approved by, or in some way registered with the Tribunal and where responsibility for these decisions should lie.

Another form of supported decision-making within guardianship is arguably provided for in the current Queensland *Guardianship and Administration Act 2000* through the operation of the principle of presumed capacity. There are ten principles that apply to all aspects of that Act (including the operation of guardianship), of which presumed capacity is one. A guardian or administrator must presume that the adult has capacity to make a particular decision unless there is evidence that s/he cannot.

Under this principle a guardian or administrator must begin from the presumption that the adult has capacity to make the decision unless it has been established that s/he lacks capacity to make those decisions. However, if a limited guardian has been appointed to make certain decisions, for example accommodation decisions, the Tribunal will have established that the person is unable to make accommodation decisions before appointing the guardian. Under such a principle, it seems that the guardian would be required to re-visit the issue of capacity when s/he commences to make the decisions about the very issues that brought the matter to guardianship. S/he would then need to continually second-guess the decision about capacity



that has already been made by a competent court during the hearing of the application for the guardianship order.<sup>25</sup>

If this is the case, the question immediately arises as to what further evidence a guardian should seek about whether the person is able to make their own decisions within guardianship and how the guardian could determine at each decision point whether the person was able to make their own decision in the matter at hand. Guardians are not qualified to assess capacity and most people would argue that independent professionals should make such assessments. If the guardian considered the person was able to make some decisions in the area, would they not then seek professional confirmation of this and take the order back to the Tribunal with a recommendation for revocation or further limitation of the order?

It is now widely accepted in Australia that capacity is context and decision-specific, except in rare circumstances such as post-coma unresponsiveness or advanced dementia, and this is already the standard approach by which capacity is assessed for the purpose of guardianship applications. The issue of a person being able to make some decisions but not others can be dealt with by means of having more specific and targeted guardianship orders. The alternative, of going through a presumption of competency process at each decision point, would appear to make guardianship unworkable. Provisions such as full consultation and respect, wherever possible, for the person's wishes would appear to better protect the person's rights and improve outcomes for them.

An obvious legal question about the presumed competence provision is that of who takes responsibility for a decision made by a represented person – the person him/herself or the guardian. This may not be an issue if the guardian thinks that the decision that the person is making is reasonable. However, if the guardian thinks it is a harmful decision, is s/he responsible for it or is the represented person responsible? As we are reminded in the UK *Mental Capacity Act*, a person should not be judged as lacking capacity just because they are making unwise decisions, but should people with diminished capacity be able to make unwise decisions within guardianship with their guardian taking responsibility for these decisions?

One of the major reasons for the development of guardianship legislation has been the recognition at law that people cannot be held responsible for decisions for which they lack capacity. One of the most positive features of our guardianship system is the acceptance of responsibility by the guardian and/or the administrator for the decisions s/he makes at a time in history when many professionals are increasingly reluctant to accept such responsibility.

At a theoretical level, the social theorist, Michel Foucault condemns “Responsibilisation” as a feature of the post-modern world. In his theory of governmentality, he identifies the increasing shifting of responsibility to the individual, meaning that government and authority are able to transfer uncertainty and risk to the individual and thus avoid responsibility while still maintaining control. Foucault argued that this is particularly taking place in the social areas of health, unemployment and homelessness.<sup>26</sup> The approach of transferring responsibility to the individual draws credibility and borrows from the thinking on individual human rights, autonomy and self-determination, making it initially appear very attractive. A principle of the presumption of competence within guardianship could be seen as an example of responsibilisation with the State transferring risk and uncertainty (unreasonably) to the person with a disability. To date, guardianship in Victoria cannot be accused of responsibilisation.

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<sup>25</sup> The Queensland Act currently operates in this way.

<sup>26</sup> Barnett, Neil “Local government, New Labour and Active Welfare: a case of ‘Self Responsibilisation’? Public Policy and Administration, Vol18, No3, 25-38 (2003).



## 7. Towards an Australian model of supported decision-making

An Australian model of supported decision-making should draw on domestic and overseas experience. It must be consistent with existing Victorian law, the Victorian Charter of Human Rights and the UN Convention on the Rights of Persons with Disabilities.

### 7.1 Proposed scope

Supported decision-making refers to formal arrangements that go beyond the informal assistance of family and friends but stop short of substitute decision-making through guardianship, administration and Enduring Powers of Attorney. Consultation, respect for a person's wishes and the promotion of a person's rights are not, of themselves, supported decision-making. Supported decision-making may, however, co-exist with substitute decision-making arrangements when different areas of decision-making are involved.

### 7.2 Suggested Principles

- People have the right to make all personal decisions that they are capable of making.
- Support and assistance with decision-making should be available to any person with a disability who seeks such support.
- The person makes the decisions. The supporters assist the person but do not take over the decision-making.
- Any supported decision-making arrangement must have the free agreement of the person and their supporters. The person with a disability may terminate the arrangement at any time and a supporter may withdraw from the arrangement at any time.
- Decisions made under supported decision-making arrangements cannot override the will of the person with a disability.
- The interests of the person with a disability are paramount in supported decision-making arrangements.
- Responsibility for decisions made may lie with the person with a disability or with the group, depending on the areas of decision and the arrangements agreed to.



## 7.3 Possible framework and forms

Supported decision-making may take several forms. A person entering a supported decision-making arrangement should be able to choose the form that suits them best. Forms of supported decision-making may be varied to meet the needs of different disability groups. The focus is on the validity of the decisions made rather than the capacity of the person. Supported decision-making arrangements should be registered and subject to safeguards to protect the person from abuse and undue influence.

Some of the possible forms of supported decision-making are briefly sketched below

### 7.3.1 Support group.

- A support group assists a person to make decisions in the areas of a person's life where they seek that support.
- It may be drawn from family, community or service providers.
- It is a long-term arrangement and deals with issues as they arise during a person's life.
- Support is unpaid and provided voluntarily.
- Major decisions are documented.
- The existence of the group and the decisions made are communicated to significant people in the person's life.
- The support group members have a role in assisting the person to implement / put into action his/her decisions.
- A person would normally have only one support group.

### 7.3.2 Representation agreement

- Involves a written agreement between the person and at least one other person.
- Areas of support/representation are identified in the agreement.
- May involve support to make decisions and representation of the person in the implementing of those decisions.
- The agreement is registered and available to those who need to know about it.
- May be based on a trusting relationship where the matters to be decided are of a personal or more minor nature.
- In based on capacity/understanding where issues of legal consent or contract are involved.
- Representatives/supporters are unpaid.



- It is a long-term arrangement that endures if the person loses capacity OR ALTERNATIVELY If the person loses capacity, the agreement must be confirmed by the Guardianship Tribunal.
- A person may have only one representation agreement.

### **7.3.3 Supported decision-making advocacy by the Public Advocate**

- The Public Advocate adopts supported decision-making as a form of individual advocacy.
- It is a time-limited arrangement for significant/major decisions.
- It deals with matters that may otherwise result in guardianship applications and is thus a targeted less restrictive alternative to guardianship.
- It may co-exist with a support network or a representation agreement.
- There is no cost to the person with a disability.
- Control and responsibility for the decision remains with the person.

### **7.3.4 Tribunal appointed assistant decision-maker.**

- The Tribunal may appoint an assistant decision-maker with the agreement of the person.
- This may be the Public Advocate, an organisation, a group or an individual.
- The Tribunal may confirm the existing support group of the person with a disability.
- Assistant decision-maker/s appointed by the Tribunal report to and are accountable to the Tribunal upon the request or order of the Tribunal.
- Notwithstanding this, the person retains control of the decisions and is responsible for them.

## **7.4 Possible safeguards**

- Support groups and representation agreements should be set up under a written agreement.
- Government or a government-funded organisation or agency should provide education, support and promotion of supported decision-making.
- There should be a register of support groups and representation agreements. The register should be held either by the Department of Human Services or the Office of the Public Advocate.
- The Public Advocate should have the power to investigate any allegation that a support group is acting improperly or against the interests of the person with a disability.



- The Public Advocate should have responsibility for resolving conflicts within a support network or Representation Agreement.
- The Tribunal should have powers in relation to supported decision-making akin to its powers in relation to Enduring Powers of Attorney. This would include the power to revoke the agreement or support network.

## 8. Key Issues and discussion

1. The literature on supported decision-making speaks of discerning the will and preferences of the person and of assisting the person to make and communicate preferences and choices. There is often the implication that if the person's will, preferences and wishes are expressed, they are actually making the decision. This is a very different approach from the capacity approach involving the elements of decision-making capacity that have been identified above. A key issue in supported decision-making is how and whether a person can be supported to make their own decisions by assisting them with those elements of decision-making where they have difficulty. How does the group decide whether the decision is a valid decision? Can a person be assisted through information, emotional support or in some other way to make their own decisions if they do not have, for example, an appreciation of the significance of the decision they are making or a reasonably consistent set of values? Whilst some in the disability community argue that everyone can make their own decisions with sufficient appropriate support, a more prevalent view, acknowledged in the United Nations Handbook, is that the capacity to make decisions is decision-specific and that in some circumstances some people will be unable to make some decisions. What is agreed is that people have the right to make those decisions they are capable of making and that the presumption of capacity should apply.
2. It is important not to underestimate the difficulty of determining whether a person is capable of making a particular decision or the difficulty of assisting a person with a disability to make and communicate their decisions without influencing or interfering with the final decision and becoming a de facto decision maker. This is especially the case when the person appears to be putting himself/herself in a situation of significant risk or is subjecting himself/herself to exploitation or abuse by another person. It is easy to say that a person has the right to make unwise decisions and that there is dignity in risk (the issue of dignity as perceived by the person and/or as perceived by the community needs further exploration). It is less easy to determine whether the person understands the risks or can foresee the consequences of their decision. In these circumstances, a form of group decision-making where all those in the group come to a "competent" decision and take group responsibility for it may have greater integrity.



3. The question of responsibility for decisions made within supported decision-making is complex. Under the classic model, the decisions are those of the person and the full responsibility for them is theirs. However, if decision-making is an *interdependent* process and if a person has a support network assisting them to make decisions, it can be argued that the members of the support network should bear at least some ethical responsibility for the decisions made, unless they formally distance themselves from the decision. The question of legal responsibility arises if decisions with legal ramifications are being made, for example decisions involving a financial contract, decisions requiring formal consent or decisions that may result in a person having a civil action brought against them. An alternative form of supported decision-making is to establish the support network as an Incorporated Association. Under this arrangement, all the members of the network take responsibility.
4. Assisted or supported decision-making can proceed most smoothly if there is agreement and support for the process amongst all those involved in the person's life. This would be particularly important if a person could establish a support network based on trust rather than on understanding. Situations where people with different views attempt to establish competing support networks are foreseeable and a mechanism for resolving this and for resolving conflicts within the network would be required.
5. It has been suggested that any formalisation of advocacy or the legislative acknowledgment of supported decision-making, especially in a Tribunal setting, may undermine the essence of what is best kept as an informal arrangement based on existing trusted relationships. This could be a concern if the establishment of formal support networks diminished respect for informal support. This is not an inevitable consequence.
6. It has also been suggested that formal supported decision-making, provided by a professional advocacy organization or a statutory body such as the Office of the Public Advocate, may undermine existing family support, especially if a Court or Tribunal makes the appointment where the person has family or friends offering to provide this. Some of these criticisms come from the Canadian experience in Ontario. Victoria has extensive experience in the provision of statutory advocacy through the Office of the Public Advocate and community advocacy organisations. Victorian guardianship legislation requires the Tribunal to consider the desirability of preserving existing family relationships when deciding who should be appointed as a guardian. This experience suggests that such problems are unlikely to be significant in Victoria.
7. There is a potential tension between the idea of a support network or circle of support operating over the long-term and a person brought into the situation on a shorter term basis to support the person in making decisions. Again, the Victorian experience indicates that this is not likely to be a serious problem. One would expect that if an informal support network could not adequately assist the person with decision-making because the arrangement needed to be more formal, it would be preferable to formalise the existing network rather than appointing an assistant decision-maker. If an assistant



decision-maker was needed, under current provisions and principles the Tribunal would be likely to first look to a member of the support network as happens with guardianship applications.

8. Supported decision-making does open up the possibility of conflict, undue influence, abuse and exploitation. The more private and informal the arrangement the more likely it is that it will go undetected and unresolved if it does occur. Appropriate external monitoring or accountability requirements may alleviate the situation but thereby impinge on the freedom of action of the person with a disability. The balancing of freedom and protection is thus an issue in supported decision-making as in all other measures designed to promote the rights of people with disabilities in our community.
  
9. The United Nations CRPD identifies supported decision-making as a new and preferred paradigm of decision-making offering an alternative to guardianship. It also considers that supported decision-making can mostly be funded by a redistribution of resources away from guardianship. Where guardianship systems and practice place large numbers of people under guardianship without appropriate safeguards, this is likely to be the case. In Australia, the number of people under guardianship and administration is relatively low and most legislative safeguards are in place. There is unlikely, therefore, to be a significant saving on guardianship costs by the introduction of formal supported decision-making. However, the dearth of supported decision-making arrangements in Australia means that this less restrictive alternative to guardianship is not widely available to people with cognitive disabilities. On this basis alone, it is an option that should be made available to people with disabilities.