Promoting Rights and Interests
Supported Decision Making

Guardianship and Administration Act 1993

Section 21 (1) The functions of the Public Advocate are—

(c) to speak for and promote the rights and interests of any class of mentally incapacitated persons or of mentally incapacitated persons generally;

(d) to speak for and negotiate on behalf of any mentally incapacitated person in the resolution of any problem faced by that person arising out of his or her mental incapacity;

(e) to give support to and promote the interests of carers of mentally incapacitated persons;

Introduction

The OPA 2012 Annual Report (page 52 onwards) described the outcomes of the South Australian Supported Decision Making trial. This project was based in the Office of the Public Advocate and was funded by the Julia Farr MS McLeod Benevolent Fund. Twenty-six people who experienced disabilities including brain injury, intellectual disability and autism spectrum disorders made agreements with family members or friends who agreed to act as decision supporters. The independent evaluation of the project demonstrated increased confidence by participants in themselves and in their decision making, a growth in personal networks, a feeling of greater control in their lives, and increased community engagement (Wallace, 2012).

The work was overseen by the South Australian Supported Decision Making Committee. The group continued to meet, to consider how supported decision-making practice might be furthered with respect to future projects and also law reform.

During 2012–2013, empirical research has continued in other locations with trials under way in NSW and the ACT, and a planned trial in Victoria. During 2013, Cher Nicholson, a committee member and former facilitator presented the South Australian work in Dublin as a guest of Amnesty International and the National University of Ireland, Galway, at a conference considering the theory and practice of supported decision making as Ireland develops its Mental Capacity Bill.

In South Australia, the Office of the Health and Community Services Complaints Commissioner has also advocated for access to supported decision making. They consider that many of the complaints they deal with involving the care of people with disability could be avoided, if the person with a disability had been given a greater voice.

The following discussion considers how supported decision making can be further developed in Australia: by considering a population-based model for supported decision making, current and future supported decision making projects, and specific options for law reform.

A population-based model of supported decision making

Supported decision making is a response to Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This Article reaffirms that persons with disabilities have the right to recognition everywhere as persons before the law, the right to enjoy capacity on an equal basis with others in all aspects of life, and requires State Parties to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their capacity.

The South Australian project illustrated the significant barriers that still need to be overcome in allowing people with disability to have greater personal control in their lives. The UNCRPD requires State Parties to recognise that disability results 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. The barriers that might stop a person making decisions in their lives can be due to the lack of assistance in making decisions, or the beliefs of others that they are unable to do so.

The South Australian project provided for a particular model of supported decision making: but how can the results of this trial be applied to upholding the rights of a much larger group of people? Using a model borrowed from population health that describes primary, secondary and tertiary interventions, it is possible to consider where interventions might occur — in particular, implementing the 'stepped model'.

Stepped Model of Supported and Substitute Decision Making

This is a quick overview of the Stepped Model, initially put forward in our 2009 Annual Report, the latest iteration of which is illustrated in full in our 2012 Annual Report. Below is a simplified version.

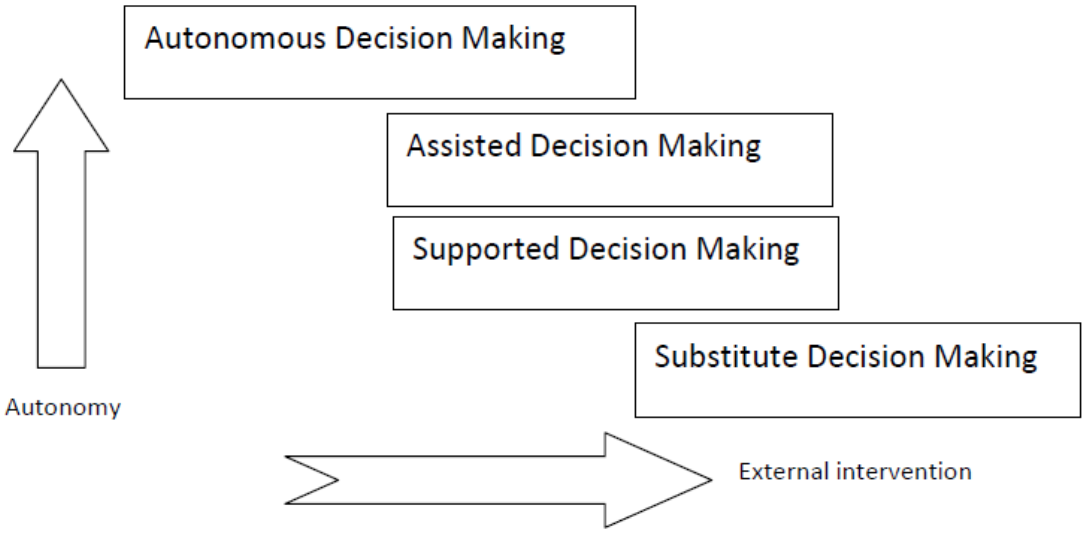

Figure A11: A simplified diagram illustrating the Stepped Model of Supported and Substitute Decision Making. Y-axis: increasing autonomy in a person's life; X-axis, increasing intervention in the life of a person by others.

In stepped models, if a necessary step is missing, the response of a system is more likely to 'fall to the right' so that it is excessive and disproportionate to need. Currently, what Article 12 describes as State Parties' obligation to provide appropriate measures to support a person to exercise their own capacity may not be available. In particular, if assisted and supported decision making is not available, people will then turn to others to make decisions, either on an informal basis or through formal guardianship. Therefore, personal decision making rights can be lost; and the more intensive external interventions delivered instead, by making an individual more dependent, may ultimately be a greater financial cost to the State.

This model distinguishes assisted decision making from supported decision making. Assistance can be delivered by anyone involved in a transaction with a person who has a disability; it may be a disability worker, health workers, bank worker, retail employee — whoever. In contrast to assisted decision making (applying this description), supported decision making occurs when a third person is invited by the person who has a disability to support their decision making, attend meetings, communicate decisions and perform other tasks associated with decision making.

We suggest that there should be a broad expectation in our community that assistance be provided wherever possible. This might mean offering time for a longer discussion, a second meeting, having plain English material, video explanations or arranging communication assistance. The UNCRPD Article 5 Equality and Non-Discrimination would consider such assistance "reasonable accommodation."

A population model of Assisted and Supported Decision Making

In this context a population model is proposed:

INTERVENTION LEVEL	DESCRIPTION OF INTERVENTION	TARGET POPULATION
Primary Universal Interventions	Education Stigma Reduction	Entire Community
Secondary Interventions	Provision of assistance Engaging of a supporter on an ad hoc basis when required	Disability sector — individualised funding facilitators Health sector Justice sector Education and training Financial sector
Tertiary Interventions	Facilitation of Supported Decision Making Agreements. Education & training of those involved in secondary-level interventions.	Specialist non-government providers. Some specialist individualised funding facilitators may develop these skills.

Figure A12: A Population-based Model of Assisted and Supported Decision Making.

Primary interventions: At this time we have done little work in this area. To uphold rights all citizens must know that everyone, including people with a disability, are entitled to equal recognition before the law and if necessary, receive helpful assistance from others as they work, study, shop, engage in recreation — assistance that is useful, that is free of condescension and delivered in a rights affirming rather than a begrudging way. This could be part of disability awareness education for school students, but also be a component of the training of people in different fields, whether it be education, the financial sector, law enforcement, the taxi industry and so on. For some groups, communication aids can help in this task. Article 12 could also be a specific focus of future community-wide disability awareness campaigns.

Secondary interventions: People working in particular industries will need greater skills in either providing assistance or working with a potential supporter. If required, supporters might be invited on an ad hoc basis, to support a person make a particular decision or provide support for a group of decisions. This is not as formalised as the intervention that was used in the South Australian project where an agreement is signed, but the principles still apply, including an understanding of the role of the person receiving support and that of their supporter (described

on pages 54 and 55 of the OPA 2012 Annual Report). A person offering support on an ad hoc basis must be able to fulfil their duty to the supported person and not use this as a way of advancing their own interests.

Anyone working in a range of industries, such as disability services, health services, justice and finance might potentially need more training in assisting people to exercise their capacity and in the use of their supporters.

Tertiary interventions: This reflects the work of what in the future might be the specialist supported decision-making sector, a sector that is yet to exist but would be similar in practice, to the work of the facilitator in the South Australian trial. . This sector could be small, as its primary purpose would be to guide and train others and to facilitate formal supported decision making agreements, particularly in complex situations. In a state the size of South Australia, it might comprise less than a handful of practitioners. Some staff employed to assist people to develop individualised funding plans could also develop their specialist skills in this area. Because these staff are involved in planning rather than provision of services, there is less likelihood of a conflict of interest in facilitating supported decision making agreements.

We consider that this population-based approach helps define a future role for supported decision making facilitators, given that while supported decision making principles might be broadly applied, only a smaller sub-group will need the specialist tertiary intervention.

However, with respect to the appointment of a guardian, we suggest that supported decision making can only be considered to have failed, or not be suitable, if the highest level tertiary intervention has been tried.

Because of the breadth of supported decision making, applicants for guardianship can say that they have considered it, or tried it; in reality, what may have been considered or tried is only the secondary ad hoc intervention, which may or may not have been applied with vigour, if the applicants believe that only a substitute decision maker will do. This is why we consider that a formal, supported decision-making agreement needs to be considered in such circumstances.

Legislative reform

The Committee has developed recommendations for legislative reform which have been presented by the Public Advocate to the Attorney-General, under the provision of s 21 (1) (g) of the *GAA*. This section gives power to the Public Advocate to monitor the administration of the *GAA* and, if he or she thinks fit, make recommendations to the Minister for legislative changes.

Separate to the need to recognise supported decision making, there are other practical reasons for the *GAA* after 20 years to be opened up to Disability reform. Aligning principles in the *GAA* with those in the *Advance Care Directives Act 2013*, and ensuring that the approach in the guardianship and administration sector is consistent with developments in reform in disability, aged care, and mental health are all reasons to consider reform of the *GAA*. For example, this section has already referred to the expectations of decision support included in the legislation and rules underpinning DisabilityCare Australia. We have also suggested practical changes to

the sections on restrictive practices (see the section on Detention in Aged Care in this Annual Report).

With respect to supported decision making, there are two components to the recommended legislative changes. First, by modifying the principles of the *GAA,* so that key principles in the Act, which are identical to the *Advance Care Directives Act 2013*, would require supported decision making. The second would be to add new sections to the Act to recognise supported decision making arrangements.

The first component of legislative change: The addition of a supported decision making principle.
This could be achieved in the *GAA* by adding a key principle of the *Advance Care Directives Act 2013* Section 10 (d) which requires:

> (d) 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;

This Office has in previous years made recommendations that the Act be amended to include a principle to underpin support instead of substituted decision making where possible. We think that the arguments to do so are now more compelling since the South Australian Parliament's support of the *Advance Care Directives Act 2013*, as well as the outcome of the evaluation of the Supported Decision Making trial. As mentioned in our 2009 Annual Report, the United Kingdom Mental Capacity Act 2005 contains a requirement to consider supporting decision making first, and this provision has been a significant driver of supported decision making practice in Britain. The only further work required is to consider how the principle can be applied to financial decisions, as the *Advance Care Directives Act 2013*, on which the suggested principle is based, does not consider financial decisions, whereas the GAA does.

The second component of legislative change: Specific recognition of supported decision making arrangements
This Office supports the recommendations of the Victorian Law Reform Commission (VLRC) for supported decision making agreements to be recognised, and the roles of supporters codified.

The legal recognition that a decision made with a supported decision making agreement can be considered to be the decision of the person, would give supported decision making a legal standing equivalent to guardianship. For example, when an organisation asks a client to choose between two options that might involve risk, if there is any doubt about a person's capacity, currently guardianship can be the only option for risk managers in an organisation to remove any ambiguity. Legal recognition of decisions made with supported decision making would provide this clarity. At the same time, legal provisions can codify the duty of supporters towards the person that they support, and protect against abuse.

The details of a potential South Australian proposal, based on the VLRC recommendations, are detailed in the following table.

Proposals to Recognise Supported Decision Making Agreements and the Roles of Supporters (based on VLRC (2012) recommendations modified for SA)

- This would necessitate the addition of a small number of new sections to the *GAA* to recognise support arrangements. These could be grouped into a new part of the Act.
- **Recognition of the appointment of supporter**
  - A new appointment known as a 'supporter' should be introduced into the *GAA.*
  - A person supported under the arrangements should be known as the 'supported person.'
  - The arrangements would support personal decisions — in the areas of health, accommodation and lifestyle.
  - A person should be able to appoint a supporter by agreement if they have the capacity to do so.
  - Where a person is unable to appoint a supporter, the Guardianship Board can appoint someone who will be able to support a person to make decisions.
- **Recognition of decisions with support**
  - Any decision made with the assistance of a supporter or communicated by or with the assistance of a supporter within the authority of the appointment or order should be recognised as the decision of the supported person for all purposes.
- **Selection of supporter**

  If appointing a supporter, the Guardianship Board must take into account:
  - The wishes of the person; the desirability of preserving family and other relationships of importance to the person; the nature of the relationship between the person and the proposed supporter, and in particular whether the relationship is characterised by trust; the ability and availability of the proposed supporter to assist the person to make the decisions about the matters to be referred to in the order; whether the proposed supporter will act honestly diligently and in good faith in the performance of their role and whether the proposed supporter has a potential conflict of interest in relation to any of the decisions referred to in the role, and will be aware of and respond appropriately to any potential conflicts.
  - People in a professional relationship with the person should not be appointed.
- **Authority given to supporters**
  - To access, collect or obtain or assist the supported person in accessing, collecting or obtaining information.
  - To discuss the information with a supported person in a way the person can understand.
  - To communicate or assist the supported person to communicate, and to advocate for implementation of the decision.
  - The appointment or order should specify which of these powers the supporter can exercise.
- **To avoid doubt the law should specify that**
  - The supporter is not authorised to make decisions on behalf of the supported person.
- **Responsibility of supporters**
  - Assist the person to make the decisions specified in the order.
  - Act honestly, diligently and in good faith.
  - Act within the limits of the appointment.
  - Identify and respond to conflict of interest, ensure that the supported person's interests are given paramount consideration, and seek external advice where necessary.
  - Respect the confidentiality and privacy of the supported person by only collecting relevant and necessary information, and only disclosing information with the supported person's consent.

Are we ready for law reform now or is more empirical research required?

In June 2013, Carney and Beaupert published in the University of New South Wales Law Journal, a considered analysis of what is required to progress Supported Decision Making, considering a phenomenon which "…uncomfortably straddles the macro-level of governance and the micro-level of individual citizen relation". (Carney & Beaupert, 2013)

These authors observe, as our Office did, that most articles and reviews on supported decision making adopt "standard, normative, doctrinal or policy analysis methodologies" rather than having an evidence-based focus. Their conclusion, on reviewing available literature including the evaluation of the South Australian trial, is that to date there has only been minimal research on practical implementation of supported decision making. They observe that the "issues at stake for people with cognitive and psychosocial disabilities and the public interest are too significant and potentially grave" to be solved by muddling through and normative arguments (i.e. those made without empirical data). They argue for more empirical research and pilot programs. (Carney & Beaupert, 2013)

In a foreword to this journal, former Chief Justice of the High Court, Sir Anthony Mason, said, "I also agree with the authors' conclusions that proposals for supported decision-making must be based on empirical evidence-based research and pilot programs which are presently lacking. As things currently stand, the proposals seem to reflect little more than ideals that have not been carefully thought through, with the risk that they will result in experimental law making". (Mason, 2013)

How does this sit with the recommendations to the Attorney-General for law reform made by our Supported Decision Making Committee through the Public Advocate?

We would suggest that the first part of our recommendation, to have an additional principle requiring support, is not controversial and having such a principle consistent with international rights obligations and other existing legislation both here and elsewhere, would not be experimental law making. If only this was achieved for the time being while more research was conducted, we would still be satisfied, given the United Kingdom experience of implementing such a principle

The measures that we see that may still be subject to debate, given the analysis of Carney and Beaupert, and commentary by Mason, are reforms that implement specific provisions for supported decision making agreements and the appointment of supporters as is the case in Canadian legislation and in the VLRC recommendations for statutory supported decision making provisions.

The Public Advocate agrees with Carney and Beaupert's conclusions about the need for more empirical research, and that this so far has been limited.

However, should more substantive law reform, in particular the legislation of provisions to recognise support arrangements be delayed while such research is undertaken? Our answer would be "No". An alternative solution would be to formally evaluate new laws as they are put in place. This could be done through prospective research, based on partnerships between academic institutions and providers. The driver and benefits of such research would be so powerful, that it would be likely to obtain competitive research funds. Too often, we know that a

review of a new Act is needed but information is collected retrospectively after a review starts some years after an Act has been operating, whereas the research to evaluate an Act could begin prospectively from day one of operation. A prospective research approach, as an alternative strategy, would ensure that people who are affected by new laws can be interviewed at the time that they engage with the law and the supported decision making process.

Another reason to proceed in this way is that supported decision making is a collection of different interventions in its non-statutory and statutory forms. While findings from empirical research on a non-statutory form can be extrapolated onto how a potential law reform might operate, they still will only ever be an approximation.

Another reason is that we risk a double standard in evidence-based law making if we apply an evidence test to rights-affirming measures that has not been applied to historical rights-removing laws. As a society we have been content to see parliaments legislate for coercive measures applied against people with disabilities that have little empirical evidence to support their use. An example of this is the widespread use in Australia of community treatment orders for people with mental illness, although there is a lack of empirical evidence to support such use (Burns et al., 2013). It would be unfortunate that a measure such as supported decision making, designed to give back rights to individuals, is expected to rigorously justify itself through empirical research, while traditional measures that take away rights do not.

So, Mason's (2013) reference to "experimental law making" could be seen as a positive, if innovative measures that are widely supported and based on the expectations of international agreements are then in their practical application subject to research evaluation that feeds into a legal review of their operation. The work of the South Australian trial could be replicated with larger numbers and applied to statutory agreements, if laws were changed. This could herald a new approach of evidence-based law making that is empirically evaluated.

At the same time, there are other opportunities for empirical research associated with DisabilityCare Australia. Given that the underpinning legislation and the Nominee Rules expect supported decision making, its use and implementation as people develop care plans could be evaluated. Because South Australia's trial involves children and not adults, any evaluation work of this type will need to be undertaken in the other states.

Summary

Further actions that could occur to further the implementation of Article 12 in South Australia would include:

- Applying a population approach that provides for education about rights and decision making for the broader community, skills in assistance and support for people who work in relevant sectors, and a small tertiary supported decision making service.
- The addition to the GAA of a new principle requiring support where possible prior to considering the use of substitute decision making.
- The addition of a new section to the *GAA* that provides for supported decision making agreements, recognises decisions made with such agreements, and describes obligations of supporters.

Supported Decision Making Committee

A Supported Decision Making Committee was established in February 2010.

It was formed under the provisions of *s21(3)* of the *Guardianship and Administration Act 1993,* which allows the Public Advocate to establish committees for the purpose of providing him or her with advice in relation to the performance of any of his or her functions. The terms of reference for the committee were published on page 104 of the 2009–2010 Annual Report.

The contribution of the members of the committee listed below is acknowledged.

With the cessation of the Supported Decision Making trial, the committee considered how to further advance the practice and uptake of Supported Decision Making, including considering the role of legislative change, the development of further resources to aid practice, and assisting other projects and practitioners applying supported decision making.

The committee membership is starting to change. Thank you to those members who have served during the trial.

The membership of the Committee is as follows:

John Brayley	*Chair*
Robbi Williams	
Graham Mylett	
Tiffany Bartlett	
Margi Charlesworth	*Until December 2012*
Ian Cummins	
Dell Stagg	
Margaret Brown	
Ian Bidmeade	
Helen Mares	
Julie-Anne Harris	*Until March 2012*
Andrew Sarre	*From March 2013*
Elly Nitschke	
Di Chartres	
In attendance	
Cher Nicholson	*Attended as Senior Practitioner and Project Coordinator, Supported Decision Making Project* *(until November 2012)* *Now a member of the committee in her own right, December 2012 onwards*

Heather Linton	*Attended as Peer Worker* *(until November 2012)* *Now a member of the committee in her own right December 2012 onwards*
Margaret Wallace	*Attended as Independent Evaluator* *(until October 2012)*
External reviewer and commentator	*John Chesterman,* *Manager Policy and Education* *Victorian Office of the Public Advocate*

The Public Advocate was an invited speaker at a forum on Supported Decision Making in Brisbane, in June 2013, organised by Queensland Advocacy Incorporated and the Queensland University of Technology Health Law Centre.