

**Office of the Public Advocate
South Australia**

**RESPONSE TO THE ALRC ISSUES PAPER: EQUALITY, CAPACITY AND DISABILITY
IN COMMONWEALTH LAWS**

Introduction

The Office of the Public Advocate is an independent statutory office of the South Australian Government. The functions of the Public Advocate are determined by provisions of the South Australian *Guardianship and Administration Act 1993*. The Office has advocacy, guardianship, education and investigative roles.

This submission is based on our independent functions of promoting rights, reviewing programs, giving advice on appropriate alternatives to taking action under the *Guardianship and Administration Act*, monitoring the administration of that Act, and making recommendations to the Minister about legislative change. This submission is the independent view of this Office and does not seek to put the position of the South Australian Government.

We note that the Australian Law Reform Commission (ALRC) inquiry has a focus on Commonwealth laws, but will also involve consideration of state and territory laws and practices. It is our observation that issues of principle, practice and culture that determine the extent that legal capacity is recognised and support provided are similar across settings, and therefore different jurisdictions. So for example, processes developed to support personal decision making in the context of state guardianship law, can also be applied to decision making in the context of Commonwealth law, such as the *National Disability Insurance Scheme (NDIS) Act 2013* and the *National Disability Insurance Scheme (Nominees) Rules 2013* which ask participants in that scheme to make decisions about personal goals and service choices.

The Supported Decision Making Project

The Office of the Public Advocate has completed a Supported Decision Making trial funded by the Julia Farr MS McLeod Benevolent Fund, overseen by the South Australian Supported Decision Making Committee comprising members with professional and/or lived experience of disability. This trial, the first of its type in Australia, facilitated 26 people with disability to set up supported decision-making agreements with either family members or friends, who agreed to provide decision support. The trial has been independently evaluated. A summary of the trial that describes the intervention and the key results is included in the 2012 Annual Report of the OPA presented to the South Australian Parliament; the relevant chapter is reproduced in Attachment 1 of this submission. The evaluator concluded that the supported decision-making intervention delivered specific benefits to most of the participants. There was a growth in support networks, a feeling of greater control in the persons' lives and greater community engagement. The evaluator said that supported decision making was both a companion process and viable alternative to substitute decision making for participants who were initially on guardianship orders (Wallace, 2012).

Underpinning this work is a conceptual model — the “Stepped Model of Supported and Substitute Decision Making”, which is also illustrated in Attachment 1 (page 58). There are a range of ‘steps’ that might meet the needs of different people. These steps include the non-statutory supported decision-making arrangement used by the people in our trial, as well as statutory supported decision-making appointments, and co-decision maker arrangements that are available in some Canadian jurisdictions. While the non-statutory model used in the South Australian trial was effective, it is the view of the South Australian Supported Decision Making Committee that statutory arrangements are required. Recognition in law of the role of supporters, recognition of the supported decision-making appointments (either by the person themselves in signing an agreement, or by tribunals) and recognition of the decisions made using such arrangements, can

ensure that people will be offered decision support when required, have decisions respected, and that more intrusive substitute arrangements are not unnecessarily put in place.

Overcoming attitudinal and environmental barriers

This work can only be fully understood in the context of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) definition of disability. 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. While supported decision-making interventions might notionally address a person's impairments, most of the work is in tackling attitudinal and environmental barriers. In particular, overcoming attitudinal beliefs that a person with a disability cannot make a decision, and addressing environmental barriers, such as a lack of practical decision-making assistance and support. With this in mind, we have recently described a population-based model of how Article 12 of the UNCRPD could be implemented at a primary, secondary and tertiary level. This model has a focus on reducing stigma, and ensuring that assistance and support is available when needed. The model has been written up in our 2013 Annual Report; a copy of the relevant chapter is reproduced as Attachment 2 of this response.

Disability rights and Aged rights

Most innovation in the area of supported decision making has arisen in the context of disability rights. Yet, the concepts and the approach are just as attractive to older people, and applicable to the needs of people with dementia.

More work is needed applying supported decision making to the needs of older people, as empirical work so far has focused on younger people. In some overseas jurisdictions, supported decision-making arrangements can be used by people with dementia.

Our Office is currently seeking funding from a research foundation to undertake a trial of supported decision making for people with a diagnosis of dementia. It is expected that people in the mild to moderate phase of their illness will use supported decision making to retain personal decision-making authority for as long as possible, and then for advance care directives to be activated when the person no longer has capacity.

Current role of public guardianship

It is our observation that Public Guardian officers have a good reputation for respecting their clients and upholding rights. However, much of their good work is not related to substitute decision making per se, but to advocacy, and ensuring people are able to access services.

Advocates/guardians in statutory guardianship offices generally seek to use a supported decision-making approach wherever possible, but by the nature of their guardian appointment they have final legal responsibility for the decision made. There are some exceptions, but in general while a person's wishes may be upheld, the person is not necessarily making the final decision.

A person should not need to lose their recognition before the law to receive this type of service, whether it is sought voluntarily through improved access to advocacy services and case coordination, or through appointments of an advocate/guardian to facilitate a supported decision-making arrangement if that will work.

In responding to the ALRC, many key issues are raised by Question 1, which we have endeavoured to answer in detail.

Question 1

Australia has an Interpretative Declaration in relation to Article 12 of the United Nations Convention on the Rights of Persons with Disabilities. What impact does this have in Australia on:

- a. provision for supported or substitute decision-making arrangements; and*
- b. the recognition of people with disability before the law and their ability to exercise legal capacity?*

It is difficult to address this question without considering the definitions of supported and substitute decision making, and addressing the suggestion by some that the convention does not allow for substitute decision making. Linked with this is a tendency in Canadian and European discussions to blur the common English meaning of support and substitution which may have a legal and philosophical basis, but we do not consider to be very practical.

The need for practical definitions of Supported Decision Making

In delivering the Supported Decision Making project, we sought to have practical definitions of what is understood by community members participating in this project to be supported decision making. In particular, the person receiving support needs to be aware that they are making the final decision, not the supporter. A key element in educating supporters is that they have a support role only: the supporter is not the decision maker, and is educated as such on support strategies, and how not to inadvertently become a substitute decision maker in this role. This approach is tangible, and consistent with the requirement of Article 12 that people be supported to exercise their capacity.

The stepped model still requires access to substitute decision making, for people who cannot be supported to make their own decisions. Such an intervention should be one of last resort, and ideally we consider that a requirement similar to that of the Mental Capacity Act 2005 (UK) should be applied; a person is not to be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success. When delivered, such substitute decision making needs to be rights-based. The stepped model minimises and prevents substitute decision making, but it does not eliminate it, and it recognises that substitute decision making still has a role.

In contrast, internationally, the term Supported Decision Making has not been defined and in our observation has been applied to any form of decision making that is respectful of the person's will and preferences, and upholds rights. This is reflected in the ALRC discussion paper (point 66 on page 30) which refers to the United Nations Committee for the CRPD draft general comment that Supported Decision Making can be 'a cluster of various support options which give primacy to a person's will and preferences and respect human rights norms.' Using this broader definition, it is possible, for example, for a "supported decision" to be made for a person who is in a coma, based on the person's known will and preference. However, this defies the plain English meaning of the word 'support'. We would call this a substitute decision made using a substituted judgement principle: a decision that can be respectful, dignified, upholding rights, but ultimately a substitute decision.

It is not helpful for such decisions to be confused with the term 'supported' decision making. The clear cut, plain English, delineation used in our stepped model, makes supporting capacity a clear practical task for supporters who are not authorised to be substitutes in that role.

The need for an interpretative declaration

We have concerns with the wording of Australia's current declaration and question the need for a declaration.

With respect to the wording, following from the arguments raised in the previous section, we find unhelpful the terminology in Australia's declaration that equates fully supported with substituted

decision making. In particular the declaration uses the word ‘or’ rather than ‘and’ when it says “...that the Convention allows for fully supported or substitute decision making arrangement”; implying that fully supported and substituted are the same, which we consider they are not.

As for the need for such a declaration, we note that Part 4 of Article 12 provides for safeguards and limitations on measures that relate to the exercise of legal capacity. It is our reading that this would include measures that relate to substitute decision making. We understand, as stated by the ALRC at point 25, that some commentators argue that Article 12 does not allow for substitute decision making. We know that some authors say that because substitute decision making is not specifically referred to in the Article then it is not permitted (as discussed by Gooding, 2012). However, the protections in part 4 of Article 12 are those that make sense as protections for substitute decision making as a “measure relating to exercising capacity”.

Although we question the necessity for a declaration, presumably Australia and other countries have seen the need to have an interpretive declaration, no doubt based on considered legal advice. The challenge then, if we are to have a declaration, is to ensure that it fulfils its legal purpose but does not unnecessarily slow change in giving people with disability equal rights. A declaration can be an impediment if it creates a sense of complacency that our existing substitute arrangements already fully meet the expectations of the UNCRPD, and there is no need to change practices.

There is a parallel to what occurs at an individual level with our experience in the trial. Many people, such as service providers and families, when first confronted with the idea of supported decision making said they are already doing it. Often this was not the case; the person with a disability had little personal authority over life decisions and the intervention led to considerable change and adjustment by all parties. The same could apply to supported decision making at a state or national level.

Arguably, Australia’s substitute decision making mostly attends to the safeguards listed in Article 12 (4). However, through amendment, such legislation could proactively encourage decision support arrangements, and require that they be tried prior to considering a substitute appointment.

Impact in Australia of the Declaration

We would suggest that Article 12 will only be implemented when supported decision making is available routinely to people with disabilities in Australia. No person should be subject to a substitute decision, whether it be made by an informal substitute decision maker, by a substitute decision maker appointed by an advance directive, or by a tribunal-appointed substitute decision maker, unless all practical attempts to support a person to make their own decision have been tried first.

For this to happen routinely, it needs to be reflected in key state laws that affect decision making in particular: guardianship and administration legislation, medical consent law, and laws that establish advance directives. Such law forms the foundation for both informal arrangements where relatives and others can be asked to make decisions, as well as making provisions for the formal appointment of substitutes. These state arrangements in turn determine how people make decisions about all aspects of their lives — including in their dealings with Commonwealth government departments and with Commonwealth funded services. If such legislation were to recognise and require supported decision making, then the foundation would be laid for a system of supporting people’s capacity throughout the community. This flow-on effect is directly relevant to how Commonwealth departments operate as they provide services to people with disabilities.

Because of the widespread perception that our guardianship and administration laws are already UNCRPD-compliant, the case for law reform has had to be based on one of promoting rights, and providing alternatives to guardianship rather than meeting a pressing need to achieve compliance with the convention. Perhaps for this reason there has been no UNCRPD-based reform yet in this key area. Just because we consider current substitute decision making is compliant with the

convention does not mean that all of our current decision-making practices are compliant, particularly given the frequent unavailability of supported decision making.

Yet there are many positive stories in the last five years that relate to work to implement Article 12 in different jurisdictions.

There have been empirical trials of supported decision making in South Australia, the ACT, and NSW, a trial commencing in Victoria and planned for Western Australia. There has been interest in supported decision making from NGO advocacy agencies, public guardians, tribunals, the Public Trustee, a Disability Commissioner, and State disability departments. The Victorian OPA has a longstanding interest in this area and hosts a national group of parties interested in supported decision making.

Disability reform both at a Commonwealth and state level with its focus on personal choice and authority has fostered an interest in supported decision making. Nationally, the NDIS Nominees Rules refer to support. It is not necessary to appoint a nominee “where it is possible to support, and build the capacity of, participants to make their own decisions for the purposes of the NDIS”.

In South Australia there has been a strong policy basis in both disability rights and the rights of health care users, emanating from the *Strong Voices* disability plan, and a review of advance directives.

As a result, recent amendments to the *Disability Services Act 1993* place decision making rights at the top of the list of objectives. The first object of the amended Act is to acknowledge and support the rights of people living with disabilities to exercise choice and control in relation to decision making. The Act also requires services to have policies that ensure the safety and welfare of persons using the disability service. One example is a policy addressing “supported decision making and consent.”

The *Advance Care Directives Act 2013* includes a principle (Section 10 (d)) that requires 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.

In this context, hopefully it will not be long before jurisdictions amend guardianship and administration legislation to include similar principles as well as the recognition of supported decision-making agreements.

Question 2.

What changes, if any, should be made to the National Disability Strategy 2010–2020 to ensure equal recognition of people with disability before the law and their ability to exercise legal capacity?

Part 2 of the National Disability Strategy ‘Rights protection, justice and legislation’ seeks to have the rights promoted, upheld and protected.

Future action 2.12 is to ensure supported decision making safeguards for those people who need them are in place, and the 2012 reports on the strategy indicates that state and territory governments are responsible for addressing these important issues in their jurisdictions.

This element of the National Disability Strategy is positive, is of considerable importance to implementing the NDIS, and should be an area of coordinated national action. Strategies to achieve uniform national best-practice would include the development of model supported and substitute decision-making legislation, to guide the next generation of guardianship and administration law reform, in the different jurisdictions, and national consistent data collection in the area. This would include the collection of data on orders made, as well as the use of enforcement

powers and restrictive practices authorised through either guardianship law or disability law, depending on the jurisdiction.

Question 3.

The ALRC has identified as framing principles: dignity; equality; autonomy; inclusion and participation; and accountability. Are there other key principles that should inform the ALRC's work in this area?

These six principles are supported, and we do not see the need to add other principles.

In particular, the principle of protection should not be a framing principle in considering work on equal recognition before the law and decision making.

This is not to say that protection is not important, because it is fundamental. In undertaking our Supported Decision Making Project, we frequently referred to Article 16 of UNCRPD, "Freedom from exploitation, violence and abuse", to guide actions to ensure people's right to safety.

Our Office, with the University of South Australia, has undertaken a rights-based project describing evidence-based strategies in adult protection to prevent elder abuse, that are also relevant to the prevention of abuse of people with disabilities (Office of the Public Advocate, 2011). Providing safety to at-risk people requires action by a range of government and community agencies, working together, beyond the role of guardianship services as substitute decision makers.

For many people, empowerment and connection with others, combined with education will be protective, whereas the opposite applies to a person who is disempowered and isolated.

Safety comes through creating safe environments, and offering effective assistance when needed.

Question 4.

Should there be a Commonwealth or nationally consistent approach to defining capacity and assessing a person's ability to exercise their legal capacity? If so, what is the most appropriate mechanism and what are the key elements?

A nationally consistent approach is supported.

As already mentioned, many Commonwealth departments and funded services rely on state appointments of substitute decision makers.

The need to address inconsistency

Because these appointments are made under different laws, with different definitions of incapacity, the rights of people to make decisions, or to be supported to make their own decisions, will depend on which state they live. For example, there are significant differences in the population rate of guardianship appointments between jurisdictions, reflecting different laws, and also different interpretation of laws by tribunals at different times depending on the prevailing rights-based or welfare-based view at the time. There can be considerable 'bandwidth' in how laws are read, and whether or not an appointment is necessary in the circumstances contributing to variation.

The Queensland Office of the Public Advocate, as part of a project examining access to supported decision making, has very usefully compared the laws in each jurisdiction.

As a separate exercise, our Office compared guardianship rates in different jurisdictions based on numbers in annual reports demonstrating significant differences:

State-by-State Comparison of Rate of Public Guardianship as at 30/6/2013
(for states in which data could be obtained from online annual reports)

State or Territory	Population 30/6/2013 100,000s	Active guardianships as at 30/6/2013	Rate per 100,000 total population
NSW	7408	1981	25.8
SA	1671	959	57.4
VIC	5738	824	14.4
WA	2517	1065	42.3
TAS	513	163	31.8
ACT	383		
NT	240		
QLD	613		

We also believe that there are different rates of full (plenary) appointments as opposed to limited appointments (limited to one area of decision making) between jurisdictions, and different rates for the appointments of private guardians. South Australia has the highest per capita rate of public guardianship, of those states where data could be obtained. It has increased from a rate of 29.6 per 100,000 population in June 2009 to the current rate of 57.4 people per 100,000 in June 2013.

This has significance for the operation of Commonwealth programs in each state and territory. For example, the NDIS Nominees Rules appropriately recognise state-based appointments, but the degree of choice and control of NDIS participants could vary from state to state depending on whether they are in a high guardianship rate or low guardianship rate jurisdiction.

Nationally consistent law on mental capacity

There are different reasons why this would be helpful. First, it would be an effective way to ensure that rights are upheld according to the UNCRPD across all jurisdictions. The law could not only define mental incapacity, but also define a range of measures for supporting a person's incapacity that are recognised nationally.

A second reason is the need for people's decision making to be recognised across states. This is relevant as people travel more or enter into transactions in different jurisdictions.

Third, it would aid monitoring and data collection in implementing the National Disability Strategy's area of policy action in rights protection. There could be meaningful comparisons across jurisdictions.

Question 5.

How should the role of family members, carers and others in supporting people with disability to exercise legal capacity be recognised by Commonwealth laws and legal frameworks?

The Office of the Public Advocate has a role of supporting and promoting the interests of carers of mentally incapacitated persons.

Most carer matters we deal with involve a lack of services for the person they care for. Many carer concerns need to be seen in this context. We also have raised with us concerns about privacy and information sharing, where information is withheld from carers by services.

The need to better uphold carer rights and interests exists across disability and health services, and is not confined to the experience of people who may have a disability affecting decision making. As expected in the Statement for Australia's Carers contained in the *Carer Recognition Act 2010*, carers need to be considered partners with other care providers, be acknowledged and treated with dignity and respect.

It should not be necessary for a carer to seek a formal guardianship appointment to be recognised by services and to get necessary information required for their carer role, or to put this another way, a person with a disability should not need to lose their right to recognition before the law, so that a carer can be heard, particularly when it already is an expectation of both state and national carer recognition Acts that carers be engaged in their carer role by services. This can mostly be dealt with through changes in practice and culture about engaging carers, not legal orders.

Conversely, carers can be concerned that should they have a conflict with a service provider, a guardianship order could be sought appointing another party or the Public Guardian to this role, as a way of taking decision-making power and authority out of their hands.

With respect to supported decision making, in the model used in the South Australian trial, people could choose one or more supporters, who were either family or friends. Supporters were friends (12), parents (10), siblings (2), grandparent (2), adult child (1), extended family (2), spouse (1) or in one case, a person was introduced to them by the facilitator. The person with a disability chose who supported them for which decisions, and potential supporters needed to indicate that they felt confident in managing any perceived or actual conflict of interest in their support role.

While a decision supporter is often a carer, this is not always the case, and a carer should not be offended if the person they care for seeks another person to provide decision support on a particular matter. This in no way diminishes the significance of the broader carer task, and the level of ongoing commitment of carers to their role.

Questions 6, 7, 8, 9, 10, 11

Disability Discrimination Act

Fair Work Act

Administrative Law & the AAT

Competition and Consumer Law

Privacy law

No comment is provided on these topics.

Question 12.

What changes, if any, should be made to the National Disability Insurance Scheme Act 2013 (Cth) and NDIS Rules, or disability services, to ensure people with disability are recognised as equal before the law and able to exercise legal capacity?

Question 13.

What changes, if any, should be made to the nominee or child's representative provisions under the National Disability Insurance Scheme Act 2013 (Cth) or NDIS Rules to ensure people with disability are recognised as equal before the law and able to exercise legal capacity?

Question 14.

What changes, if any, should be made to the nominee provisions or appointment processes under the following laws or legal frameworks to ensure they interact effectively:

- (a) the National Disability Insurance Scheme Act 2013 (Cth) and NDIS Rules;*
- (b) social security legislation; and*
- (c) state and territory systems for guardians and administrators?*

While the *NDIS Act* and the *NDIS Nominees Rules* contain excellent principles, we are concerned as to how they will be interpreted in practice.

Relying on legislated principles alone to uphold rights can have limited benefit. For example: guardians also need to apply relevant principles, but in a survey commissioned by our Office of 289 South Australian private guardians, only 43% were aware of the relevant principles, and this awareness was as low as 35% for guardians appointed by an enduring instrument (Office of the Public Advocate, 2012b)

It is possible that a similar situation might apply to plan nominees. Close attention will need to be applied to the implementation of the *NDIS Nominees Rules*, and the extent that they encourage support to enable people's capacity as opposed to potentially disempowering participants by transferring effective decision making to plan nominees. *NDIS* itself can play a role in educating nominees on their role so that this does not happen, and expecting nominees to attempt to support a participant make their own decision before taking on a substitute role.

This is not a criticism of plan nominees who want the best for their family member or friend, and may have endured many years of underfunded disability services, managing crises, and may be reluctant to disturb arrangements that are working and seem safe.

The current Plan nominee role is a global appointment, and it relies on the discretion of the nominee to limit the use of their power; in particular the power to make substitute decisions when a person cannot be supported to make their own decisions.

We suggested in early 2013 two changes to provide greater clarity to these roles, based on the stepped model, and our experience with the supported decision-making trial. First, consistent with a stepped model approach, there should be separate definitions for supported decision-making nominees and substitute decision-making nominees. Second, consistent with the decision-specific nature of mental capacity, there should be a separation of the role of nominees who support or make planning decisions from those who act as financial managers. People who do not wish to manage finances, or are unable to do so, should be able to appoint a financial manager, but should clearly retain the personal authority to make decisions about goals, and the nature of services. There is a risk with the current arrangement of appointing a Plan nominee, that a person appointed to make financial decisions might also see it as their role to sign off on other decisions.

As it is still early days in the operation of the *NDIS*, we do not know if the current nominee rules are protecting people's recognition before the law, and if the support and autonomy principles are being upheld. Because our Office is based in South Australia, we do not have any direct experience of the *NDIS* for adult clients, as the *NDIS* trial in this state is focusing on children. Lessons on the operation of the *NDIS* nominee rules will come from other jurisdictions.

Should further clarification of the roles of nominees be needed, then we would suggest our March 2013 proposal be revisited (see web link at Office of the Public Advocate (2013) in the reference list.)

In summary: our proposal would have transformed the current two categories of nominee — correspondence nominee and plan nominee — into four categories:

Proposed separation of Plan nominee to reflect supported and substitute decision making and financial management

Correspondence nominee	No change on existing proposal
Plan nominee (supported decision making)	Nominee supports the person in planning, and participates in developing the plan. Final decision making rests with the person with a disability.
Plan nominee (substitute decision making)	Nominee can make planning decisions on behalf of the participant, but still uses supported decision making where possible. (similar to the existing plan nominee).
Plan nominee (financial management)	Nominee manages the funds on behalf of the participant. Planning decisions are either made by the participant, with the support of a Plan nominee (supported decision making) or by a Plan nominee (substitute decision making). Can enter into a contract for services to be delivered

It is expected that the NDIS will also change the power imbalance between disability services and people with disability and their families by returning choice to the service user. In a traditional underfunded system, the disability case coordination system takes on a rationing role, and no matter how well intentioned a disability worker is, a power imbalance exists between the provider and consumer and carers. It was clear from the evaluation of our project that supported decision making challenges these imbalances, and at least for the first one or two people in each organisation who sign up for a supported decision-making agreement and start making decisions that challenge the status quo, these barriers take work and energy to overcome.

On the other hand, there can be mutual reinforcement in rolling out rights-based services and supported decision making. If the NDIS can reach its goals of returning choice and control to service users and families, then supported decision making will work well as a companion process, and should flourish. However, if supported decision making is implemented in a traditional underfunded system that relies on rationing and bureaucracy to control and manage demand, then the implementing supported decision making will be an uphill battle and lead to conflict and disappointment.

In our view, it is not possible to just implement one article of the convention (in this case Article 12) without working on others (such as social and economic rights). They are all interrelated.

Question 15.

In what ways, if any, do Commonwealth laws or legal frameworks relating to employment diminish or facilitate the equal recognition of people with disability before the law and their ability to exercise legal capacity?

Our Office has not reviewed this area, as it applies to Commonwealth laws or legal frameworks, or assisted employees of Commonwealth government agencies, so therefore we are unable to directly comment on this question.

In our 2013 Annual Report, we considered the topic of Mental Illness and the Public Sector Workplace (pages 41–45). This concerned South Australian public servants who had been required by their employer to undergo a medical examination, in these cases, a psychiatric examination, to determine their fitness to work, which could potentially lead to termination of employment.

While not an assessment of legal capacity per se, the issues are closely related. It is our view that such powers should only be used as a last resort, and in the interests of an employee, and performance management systems, not psychiatric assessment, should be the principal tool to protect both the interests of the employee, employer and workplace colleagues. A person should not lose their job based on a mental health assessment which they would not have otherwise lost through performance management, as this is discriminatory.

We do not know the extent that similar issues occur in other jurisdictions, but we understand that employees in other systems have expressed similar concerns.

Question 16.

What changes, if any, should be made to the Commonwealth Electoral Act 1918 (Cth) or the Referendum (Machinery Provision) Act 1984 (Cth) to enable people with disability to be placed or retained on the Roll of Electors or to vote?

Question 17.

What issues arise in relation to electoral matters that may affect the equal recognition before the law of people with disability or their ability to exercise legal capacity? What changes, if any, should be made to Commonwealth laws and legal frameworks to address these issues?

Our Office has not undertaken an analysis of Commonwealth election laws. However, we have considered the right to vote, and the interface with supported decision making. We joined with professional and mental health service users and carers to prepare an article on mental health recovery and voting, currently in press (Lawn et al., 2013).

There is synergy between the requirements of Article 12 to support capacity, and Article 5 requiring reasonable accommodation, to key elements contained in Article 29 “Participation in political and public life”. In particular, the requirements of the Article to ensure that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use, and to guarantee the free expression of the will of persons with disabilities as electors and to this end, where necessary at their request, allowing assistance in voting by a person of their own choice.

The common law presumption of capacity needs to be upheld for voting capacity. We see no need to routinely ask this question, although clearly people who are unwell may ask to be discharged from their duty to vote, and some people who are very confused may not be able to undertake the task. It is difficult to accept a situation where a person wants to vote, and knows that they are voting, who would then be stopped from doing so.

It would be a worthwhile exercise for practical supported decision-making strategies to be developed to assist and support people who might not normally participate in voting to cast their vote. This could be a potential area of future work for our SA Supported Decision Making

Committee to seek project funding, if it were possible to establish the necessary links with electoral authorities.

Question 18, 19, 20, 21 NS 22

Use of language

Holding public office

Jury service

Board participation

Identification

No comment is made with respect to these questions.

Question 23.

What issues arise in relation to access to justice that may affect the equal recognition before the law of people with disability and their ability to exercise legal capacity? What changes, if any, should be made to Commonwealth laws and legal frameworks relating to access to justice to address these issues?

In responding to this question we wish to address the matter of litigation guardianship, as our Office can receive requests to take on this role for people in the Family Court, and the Federal Circuit Court as well as for people who are responding to child protection matters before the state's Youth Court.

It is our observation that there is considerable variability in how the need for a litigation guardianship is perceived.

For this reason we ask legal practitioners to refer to the South Australian Law Society Client Capacity guidelines (Law Society of South Australia, 2012). This excellent document provides an ethical and legal basis for the legal practitioner to explore and enhance client autonomy, and then if necessary involve a support person, but only with a client's consent. On this basis, it may not be necessary to proceed with a litigation guardianship role, so we ask practitioners to first consult this guideline to see if such a step is necessary. This reference is a useful tool to uphold client autonomy, and to reduce the need for a litigation guardian as a substitute decision maker instructing a client's lawyer. This approach we see to be very much consistent with Article 12.

With respect to broader disability justice matters, the majority of our direct experience has concerned clients with a disability who are victims, alleged offenders or witnesses to a crime for matters that come before state criminal courts. The need to improve responses along the entire justice process for people with disability is now broadly recognised in the disability and justice sectors, from crime prevention, recognition, police investigation to prosecution and court processes. Our Office has had the opportunity to contribute to the development of such a strategy in South Australia. It is our understanding that similar issues apply across jurisdictions, but we have not had sufficient direct experience with Commonwealth laws or reviewed them, to be in a position to suggest specific changes.

We can see the benefit of having best-practice principles recognised nationally, and for data to be collected to allow jurisdictions to compare performance in key areas.

Also, many of the same principles of providing reasonable accommodation in justice processes extend across disability rights and aged rights. For example: there are common concerns related to specialised interviewing, the understanding of evidence given by a person who has a cognitive or mental health problem, and how best to support a person through a court process. For this reason, it makes sense to us, in making justice more accessible, to recognise that strategies put in place to assist younger persons, may also assist the aged, such as victims of elder abuse.

Questions 24-33

Evidence Act
Federal offences
Social security
Banking
Insurance
Superannuation

No comment is made on these questions

Question 34.

What issues arise in relation to health care that may affect the equal recognition before the law of people with disability and their ability to exercise legal capacity? What changes, if any, should be made to Commonwealth laws and legal frameworks relating to health care to address these issues?

We wish to address two issues: First, the determination as to whether or not a person can consent to health care and second, the need for uniform capacity-based mental health laws.

Once again, our focus in responding to the discussion issues raised is on state law (in this case consent law and mental health law) as it affects Commonwealth-funded services, and the benefit of having a uniform approach across Australian jurisdictions.

The South Australian *Guardianship and Administration Act 1993* s58 only permits a substitute medical or dental consent decision to be made when a person by reason of his or her mental incapacity, is incapable of giving effective consent, whether or not he or she is a protected person.

The significance of this is that even when a person has a health guardian appointed, the health guardian cannot be asked to consent to a decision that the person themselves could effectively make (Office of the Public Advocate, 2012c) A person may have had a health guardian appointed to make a specific decision, but have the capacity to make other decisions.

This upholds the concept of decision-specific capacity. A similar principle will continue to apply in South Australia after July 2014, following the implementation of the *Advance Care Directives Act 2013*, and amendments to the *Consent for Medical Treatment and Palliative Care Act 1995* which will uphold the principle of decision-specific capacity.

This concept of limiting substitute decision makers' interventions in this way is a good one that we would suggest should be a part of any national uniform legislation, if such legislation proceeds.

Once again, people should be supported to make their own decisions wherever possible, before considering the appointment of a substitute.

The discussion paper refers to state mental health laws. Internationally, mental health laws are beginning to incorporate concepts of mental incapacity, as opposed to just retaining traditional criteria that relate to the presence of a mental illness and risk. Australia could now benefit from new model mental health legislation that incorporates capacity criteria. Such criteria have been incorporated into the new Tasmanian Mental Health Act (from January 1, 2014) and are expected to be part of new Victorian legislation. We have put forward the need for such criteria in our submission to the review of the South Australian *Mental Health Act, 2009* (Office of the Public Advocate, 2013b).

Mental health legislation defines the operation of our mental health systems, and its role needs to be an integral part of national policy and service plans. The degree to which mental health services actively engage with their consumers on a voluntary basis will determine whether or not involuntary measures are invoked. The National Mental Health Commission itself could have a key role in developing model capacity-based mental health legislation, and facilitating the roll-out to states. To do this, the Commission itself should have its role defined in law, which is currently not the case.

Question 35.

What issues arise in relation to aged care that may affect the equal recognition before the law of people with disability and their ability to exercise legal capacity? What changes, if any, should be made to Commonwealth laws and legal frameworks relating to aged care to address these issues?

We have addressed the topic of deprivation in liberty in aged care in our 2013 Annual Report, (Office of the Public Advocate, 2013, pages 46–50).

It is our recommendation that the user rights principles of the *Aged Care Act 1997*, should specify principles aimed at minimising and where possible eliminating the use of restrictive practices. Currently there are insufficient protections.

We are also concerned that many older people are effectively detained to aged care units, without a statutory basis for their detention, and without appeal rights should they object. This occurs in jurisdictions that do not have detention provisions in guardianship law and rely on a common law justification of necessity, and also occurs in jurisdictions such as South Australia, which does have such provisions but they are under-used.

Our Annual Report suggests the use of a collaborative authorisation model put forward by the Victorian Law Reform Commission, along with the use of guardianship provisions where necessary for people who are consistently resisting and opposing restrictions whose rights would not be protected through collaborative authorisation alone (Office of the Public Advocate, 2013).

As noted earlier in this submission, our Office is currently seeking research funding for a proposal to offer a trial supported decision making service to older people who have mild to moderate dementia, in combination with the use of an advance directive that would become active when their condition is more advanced.

Question 36.

In what ways, if any, should the proposed National Framework for Reducing the Use of Restrictive Practices in the Disability Service Sector be improved?

Question 37.

What is the most appropriate approach to the regulation, reduction and elimination of restrictive practices used on people with disability at a national or nationally consistent level? What are the key elements any such approach should include?

Our Office reviewed restrictive practices in our 2011 Annual Report (Office of the Public Advocate, 2011). It is our view that the responsibility for the reduction and elimination of such practices should rest with disability services. Therefore, provisions requiring best-practice assessments and positive behaviour support plans should be incorporated in disability legislation. There is still a role for guardian consent, but guardians cannot be expected to fulfil a quality-improvement and change management role for disability services.

Given the move to Commonwealth funding of disability services through the NDIS, it would be possible to define rights and practice standards in legislation or rules that require these standards to be upheld as a condition of receiving funding.

Question 41.

How do Commonwealth laws and legal frameworks relating to equal recognition before the law and capacity affect people with disability who are:

- (a) children;*
- (b) women;*
- (c) Aboriginal and Torres Strait Islander;*
- (d) from culturally and linguistically diverse backgrounds;*
- (e) older;*
- (f) lesbian, gay, bisexual, transgender or intersex; or*
- (g) living in rural, remote and regional areas?*

Aboriginal and Torres Strait Islander People

Recognition before the law for Aboriginal people who experience a disability overlaps with the broader topic of recognition before the law for Aboriginal people. Aboriginal people with disability can face discrimination based on both race and disability. In keeping with the approach of the ALRC discussion paper that has linked the operation of guardianship and administration laws to this Commonwealth review, this section of our response will discuss the use of state guardianship and administration legislation in the context of broader policy objectives and the delivery of services.

The response will consider two broad areas: first the use of guardianship and administration law as a policy response to people who have substance use problems, which will be discussed in the context of historical and current policy responses to "protect" and control Aboriginal people; and second, the more traditional use of guardianship and administration interventions to assist Aboriginal people who have a recognised disability, interventions which can deliver significant benefit, but be hampered by a lack of available disability and mental health services on the ground.

Because of the need for responses and services for Aboriginal people to be coordinated, Commonwealth-funded Indigenous Coordination Centres (ICCs) operate in many areas that bring together services commissioned or operated by different levels of government. It is in this context that the use of state guardianship law can be discussed alongside Commonwealth services, and coercive initiatives such as compulsory income management.

At times, guardianship and administration appointments are raised as options for individuals at risk using substances who might otherwise benefit from better and more coordinated services. In this respect, the work of the ICCs and other similar initiatives that seek to bring effective, well-coordinated services to people in need have the potential to prevent the need for coercive orders, and hence the loss of recognition before the law of Aboriginal people.

Guardianship and administration can also be seen as a policy alternative to Commonwealth measures such as compulsory income management, and in many respects there is little difference between the effects of an administration order, and compulsory income management arrangement, although the latter could involve the management of the entire family income and not just that of a person who has an incapacity.

A South Australian example

To illustrate these principles, it is relevant to look at current issues concerning the Far West Coast of South Australia, and the interrelationship between service provision, coercion and the potential involuntary movement of Aboriginal people.

The Far West Coast needs an alcohol rehabilitation facility located as a priority in the vicinity of Ceduna, Yalata and Oak Valley communities. This is a recommendation of Dr David Scrimgeour, a Public Health Medical Officer with the Aboriginal Health Council of South Australia, endorsed by the South Australian Deputy State Coroner in his inquest into the deaths of six Aboriginal people at Ceduna. Dr Scrimgeour gave evidence that many people are very happy to access residential

rehabilitation if it is available in an appropriate location and that there is evidence that such services developed locally and under the control of local Aboriginal organisations give rise to favourable outcomes. He did not support the use of involuntary orders (Coroner, 2011).

However, there are no plans to provide such a facility in the West Coast. Instead, in late 2013 the Commonwealth confirmed a plan to service this region from a facility in Port Augusta. The Coroner suggested that "particularly if an alcohol rehabilitation facility were to be situated at Port Augusta or at some other location in close proximity to licensed premises or other suppliers of alcoholic beverages" that the South Australian legislature consider enacting legislation that would provide for the mandatory detention and treatment of persons with severe substance dependence".

This dichotomy illustrates the choice of approach: local and voluntary vs distant and potentially coercive with the use of detention powers.

In response, the South Australian Health Department has noted the need to consider human rights, civil liberties and social exclusion and advised that first, Country Health SA "... will consider the impact and effectiveness of the implementation of the comprehensive voluntary strategies recommended by the Coroner, prior to determining whether further strategies such as compulsory treatment measures are warranted in the Ceduna area" (SA Health, 2012). At the same time, the department would work with "...the Guardianship Board and Public Advocate on a short term project to identify opportunities to apply the *Guardianship and Administration Act 1993* to individuals with mental incapacity and who are at risk due to severe substance abuse."

This may be an uneasy situation, because if a clinician looks hard enough, and undertakes extra clinical examinations and cognitive testing, it is likely that many if not most of the people with severe alcohol dependence will also have a coexisting cognitive disorder; meaning, that significant numbers of Aboriginal people with alcohol problems sleeping rough could theoretically come under guardianship jurisdiction and be placed on orders. Traditionally, the law has only been applied to those people clinically identified as having alcohol-related brain injuries (that can typically produce executive-function problems related to frontal lobe impairment, and memory disorders) and has not been applied to the broader group of people with severe alcohol problems who may or may not have cognitive deficits that are not overtly evident to others, and therefore not routinely tested for. Estimates of the number of people in the Far West Coast who might be placed under orders are anecdotal, and it is not clear if orders might be applied for 10 more people or 30.

At the present time, new orders have not been made; there is some concern within communities about how financial administration might operate, and some service providers have a fear that people who are already voluntarily engaging with services, might become wary of attending services if they considered that by doing so, they were at risk of being placed under an order.

We are aware of positive outcomes in another state when guardianship orders have been used in such situations. However, it is our understanding that the rights-based practitioners in that program have used a supported decision-making approach, and we suspect that if legislation contained supported decision-making alternatives, then these would be sought in these situations, rather than substitute powers or powers to apply restrictive practices.

The role of substitute decision making can be more easily justified when suitable services are available but have not been taken up, and where a person is at risk. This is in contrast to the situation where orders are put in place in the absence of suitable local services, and by moving people to other places for treatment, may actually lessen the pressure for services to be delivered locally.

Addiction and a common definition of capacity

If, consistent with the discussion point in the ALRC paper at Question 4, Commonwealth and state jurisdictions commit to a uniform approach to legal capacity, then this uniform approach needs to consider how such laws are applied, or not applied, to address problems related to addictions to substances and also gambling. While these conditions are not recognised as a mental incapacity

per se, an order might be obtained based on a co-morbid mental illness or disability, where the objective in obtaining the order is not to manage incapacity due to the mental illness or disability, but to control the co-morbid addiction-related behaviours.

It is our view that the primary therapeutic approach to these conditions should be voluntary, but if laws are to be invoked, then specific laws related to gambling (e.g. barring arrangements) or substance use treatment (e.g., legislation for time-limited involuntary treatment when at risk of death from substance use) are preferable in the first instance to using guardianship or administration law based on the existence of a disability. This is because the specific addiction-related laws where available apply an evidence-based intervention or treatment, the loss of rights with any such order is either narrow in scope or time limited, and a person subject to these laws is not seen to have lost recognition before the law. Also, the use of such laws is usually associated with population-based strategies to limit access to substances or gambling, and are part of a broader plan.

This is relevant to policy discussions related to the needs of Aboriginal communities and any desire to stretch the routine application of guardianship and administration laws to people with addictive behaviours who under a common law presumption of capacity would not have otherwise been cognitively tested or had orders applied for.

Historical and contemporary policy objectives

Aboriginal people need equality of access to services, as well as recognition and empowerment for communities to take action to redress historical and social causes of disadvantage.

Given the increasing frequency of disability affecting cognition in Aboriginal communities, secondary to such causes as substance-induced brain injury, traumatic brain injury and foetal alcohol syndrome, there is a risk that significant numbers of Aboriginal people could be placed on orders, losing recognition before the law.

Historically, laws such as South Australia's *Aborigines Act 1911* legislated for a Chief Protector of Aboriginals position. Examples of powers of the Chief Protector include those to keep Aboriginal people in reserves or institutions, and of "curatorship" over the estates of Aboriginal people — curatorship being similar in nature to administration. The Act also enabled a Justice or police officer to move on Aboriginal people who were loitering in towns.

There is an ever present risk that guardianship and administration powers can be used in the same way. Here are some examples. Recently, hospital staff at a remote town spoke to a staff member of our Office because they had heard that a private guardian of an elderly Aboriginal man with dementia might be planning to move him to a fenced aged-care facility hundreds of kilometres away. The man was in well supported accommodation, but his alcohol use on the street of his home town was seen as a problem by people in this town. Our Office contacted the Guardianship Board, became the man's guardian, and decided in accordance with his wishes that he should not move, that he should continue to live in country, much to his approval and the agreement of the health staff who cared for him. We know of another man in the past who died after such a move, ostensibly because of multiple medical conditions, but also possibly because of the pain of being away from country at a time of life when he should have been there.

Another example is the misuse of Commonwealth-funded secure aged care facilities as compounds to detain younger Aboriginal adults who have substance-induced brain injuries, who should otherwise be receiving state-funded services. Aboriginal people from the age of 50 are eligible for aged care. So, in contrast to a city person of this age who, if suffering from alcohol-related brain injury, would be offered a disability package and either individual or small group accommodation, a remote Aboriginal person, aged 50, might instead be admitted to an aged care facility. This detention can be a problem for the younger person, their older co-residents and staff. Facilities can sometimes resemble compounds, enclosed by a fence, and the principal objective of the placement is keeping the person away from the pub.

The problem of forced movement of Aboriginal people also exists when young adults are moved across the state to specialty disability programs. These can be effective programs, engage people in tasks and education, and keep people out of gaol. However, it is a gap in our system that these programs are not delivered in rural and remote locations, and that young Aboriginal adults are moved away from family and country for months or years. Visiting can be limited because of cost and distance. Arguably, there would be more voluntary participation in programs if operated closer to people's homes.

Positive aspects of guardianship

As for any group of people, guardianship can be life changing and lifesaving. Families and communities can appreciate the value of having an independent public guardian make difficult decisions for a person with a significant incapacity. People at risk of death or incarceration, can be linked by their guardian with rehabilitation services that they come to appreciate, and can then make new personal plans and goals, and reconnect with culture. People under guardianship can value and depend on the assistance of a guardian, mostly operating in a supported decision-making model. The guardian, as advocate, can work with disability, mental health and exceptional needs programs to ensure that services are delivered. There are many service providers working in culturally safe models delivered by both Aboriginal and non-Aboriginal staff.

People receiving these services often have a significant incapacity. At times, western concepts of guardianship can assist fully initiated men, who retain their valued role in community. Administration orders for older Aboriginal people have also kept people safe from humbugging.

The system can work very well and be delivered in a culturally safe way upholding disability rights. If the Commonwealth and state working together deliver necessary services in regional and remote areas, then guardianship can continue to have a valued but limited 'last resort' role, and supported decision-making arrangements will also be available. The risks remain though, while service gaps exist, a coercive response may be invoked without first doing everything to provide local services that seek to voluntarily engage with people.

Should there be work in the future to develop a common understanding of mental incapacity across jurisdictions, then the impact on Aboriginal communities should be specifically considered. We think, as a general principle, any reform that requires consideration of supported decision making before invoking substitute arrangements will better uphold the rights of Aboriginal people.

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Promoting Rights and Interests

Supported Decision Making

Introduction

The background to supported decision making was discussed in the 2009 Annual Report and progress regarding the South Australian Supported Decision Making Project was recorded in our 2010 and 2011 Annual Reports. This project, based at the Office of the Public Advocate and funded by the Julia Farr MS McLeod Benevolent Fund is now completed and an independent evaluation has demonstrated the effectiveness of this intervention.

It is worth recapping why the concept of supported decision making is important. It fosters autonomy. People with a disability make their own decisions rather than having decisions made by others. Providing support is a viable alternative in many situations to substitute decision making. While formal substitute decision-making is clearly recognisable (for example, a guardianship order), more commonly, substitute decision making can be 'informal' when decisions are made for a person by family, friends or professionals. Supported decision making seeks to help family or friends take on a decision-support role, rather than a substitute decision-making role.

In our model, the person who wishes to receive support decides who will deliver that support, and for how long. It is a role that cannot be undertaken by paid workers.

All too often we hear from people with a disability that they have not been expected to make decisions. Decisions are made for the person, and there has been no opportunity to acquire decision making skills and experience. Supported decision making provides such opportunities, to the extent that for some people, a supported decision-making arrangement may only be needed while a person develops new skills and confidence. It can be a short-term intervention to provide empowerment.

The United Nations Convention on the Rights of Persons with Disabilities recognises that disability is a result of environment, and not just an individual's impairment. Attitudinal and environmental barriers hinder a person's full and effective participation in society on an equal basis with others (UNCRPD, 2006). Article 12 of the Convention recognises that persons with disabilities have the right to recognition everywhere as persons before the law. States Parties are expected to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

This intervention is fundamentally about preserving basic human rights: equality, dignity, and freedom. Some people ask us why it is necessary to have a specific intervention labelled 'supported decision making' when what are being advocated are the traditional values of personal autonomy, the least restrictive option, and the provision of support which for all of us can occur naturally.

Unfortunately, it is all too easy to revert to traditional paternalistic responses, particularly if the rights-based, less restrictive alternative is vaguely defined and somewhat aspirational. If the more intrusive intervention of guardianship is specifically defined in legislation and provided by

the state for free, there will be little incentive to consider alternatives, particularly if the exact nature of these alternatives is uncertain. Supported decision making offers a practical strategy that can be delivered. It offers a way of helping people with their decision making without needing an order.

This discussion will reconsider the Stepped Model of Supported and Substitute Decision Making, the supported decision-making approach used in the South Australian Project, and the results of that project. While descriptions of the rationale, model and results of evaluation have already been published in a number of documents on our website over the last three years, this summary in this year's Annual Report seeks to bring together this information.

The Stepped Model

The 2012 Stepped Model is illustrated in the next figure. The South Australian Project developed from earlier versions of this Stepped Model.

We first proposed a broad Stepped Model of Supported and Substituted Decision Making in our 2009 Annual Report. This model described different interventions based on the level of autonomy retained by the individual, and the level of intervention by the state.

The aim of having such options is to avoid escalation into more intrusive interventions that may not be needed. Professor Terry Carney critiqued our original stepped model in a book chapter in 2012. He noted that "...the proposal provides a more granular range of choices in place of the more binary one of making or denying guardianship..." In his article, he goes on in a prescient way to note that new legal tools cannot rectify deficits of service provision or civil society. He says that wide spectrum tools such as the one proposed by us, can "...only be judged by how well it mobilises public or private resources (such as informal supports of civil society) in accordance with peoples' individual set of values and preferences (in this and other respects); but the point here is that agency is *realised* only to the extent that resources *exist* in the external environment" (Carney, 2012, p.17).

This turned out to be very much the case in our trial, particularly when people made accommodation or support decisions in our trial that then had to be resourced. Frequently, our facilitator needed to provide advocacy herself or link clients with advocates so that people having made a decision could see it effected. In the future, reforms such as the NDIS will be significant in addressing these current deficits so that reasonable expectations emanating from decisions will be met.

In 2010, the Stepped Model was modified in that year's annual report to provide more detail about different forms of supported decision making, to define assisted decision making as distinct from supported decision making, and incorporate co-decision making. The latter followed communication between our Office and Professor Neil Rees and his team at the Victorian Law Reform Commission who were considering co-decision making models.

This year, a minor alteration has been made in the axis label of the diagram, which is the only difference between the 2010 model and the 2012 model. The X-axis previously described "increased care and protection and increased intervention by the state" as the model described each step from autonomous decision making, through different forms of supported decision making and onto guardianship. This axis now just reads "increased intervention by the state" and no longer refers to protection. It is wrong to equate increased state intervention with

increased protection, because a person can still have extensive state involvement such as through guardianship, and still be isolated. For example, a person who has more personal control in their life through supported decision making, and more community connections through their links with supporters may be better protected than a person who is isolated and powerless. The latter can occur when a person considers they have no option but to comply with the demands of others.

It is worth recapping the distinction between assistance and support in this model. Assistance can be provided by anyone — staff at a hospital, disability providers, or people in any community organisation. It may take the form of taking time to give explanations, repeating information, and having information sheets in simple language that use diagrams. It is an obligation placed on our community to provide such assistance. Assistance is a form of reasonable accommodation, as described in Article 5 of the UNCRPD “equality and non-discrimination”.

Supported decision making, however, relies on a person asking a trusted friend or family member to regularly provide support over a particular area of decisions.

Supported Decision Making Model used in the South Australian Supported Decision Making Trial

The project facilitator established agreements between a person wanting support, and their nominated supporters. Education was provided to participants to determine if they wanted supported decision making, and to provide support in their initial key decision — whether or not to proceed with supported decision making, and choosing a supporter. The different roles are described in the following table.

Supported Decision Making — Participant Roles
The person receiving support needs to be able to:
Express a wish to receive support
Form a trusting relationship with another person(s) (supporter or monitor)
Indicate what decisions they may need support for
Indicate who they wish to receive support from for which decision
Express a wish to end support if that time comes
Be aware that they are making the final decision and not their supporter (take responsibility)

The decision supporter needs to:

Respect and value the supported person's autonomy and dignity

Know the supported person's goals, values and life experiences

Respect the individual decision-making style of the supported person and recognise when and how support may be offered

Form a trusting relationship with the supported person

Be willing in the role of supporter, to fulfil their duty to the supported person, and not use this role as a way of advancing their own interests or any other person's interests

Be able to spend as much time as is required to support a person make each decision

Assist in the expression of that decision to others if required

Supported Decision Making — Participant Roles

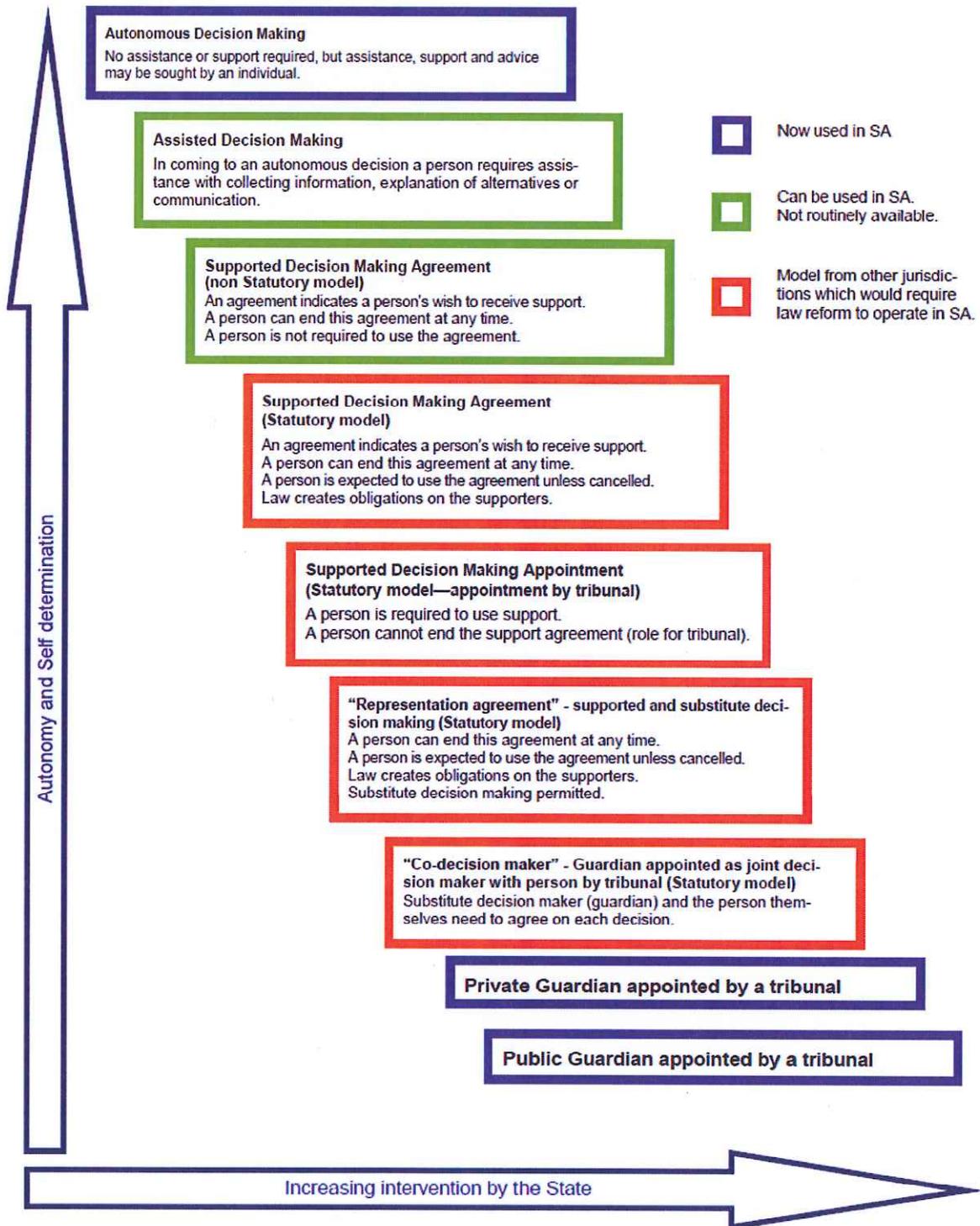
The South Australian trial involved setting up an agreement between a person with a disability and a family member or friend who would act as a decision supporter. It is a non-statutory model. Therefore, in looking at the successes of the trial, and also its weaknesses, it is important to acknowledge that this is just one form of supported decision making. For example, this trial could not accept individuals where there was significant conflict with families and friends, to the extent that some members of a family may not recognise and accept the decisions made with support. In a *statutory* model, where supported decision making, and the decisions made with this support are recognised in law, it would permit supported decision making to operate in these settings.

As a new intervention in South Australia, the project was submitted to the SA Health Human Research Ethics Committee for approval.

This project was subject to independent evaluation. Margaret Wallace of Muirgen Nominees was the successful tenderer for the evaluation — the outcomes of which are reported later in this section. The approach of using an empirical trial has not been common in guardianship law reform overseas. More often, systems are designed and then legislated for. The trial approach however, has now been adopted in other jurisdictions in Australia as a way of developing models to inform future evidence-based law reform.

Equal Recognition under the Law

A Stepped Approach to Supported and Substituted Decision Making



Participants and Decisions Made

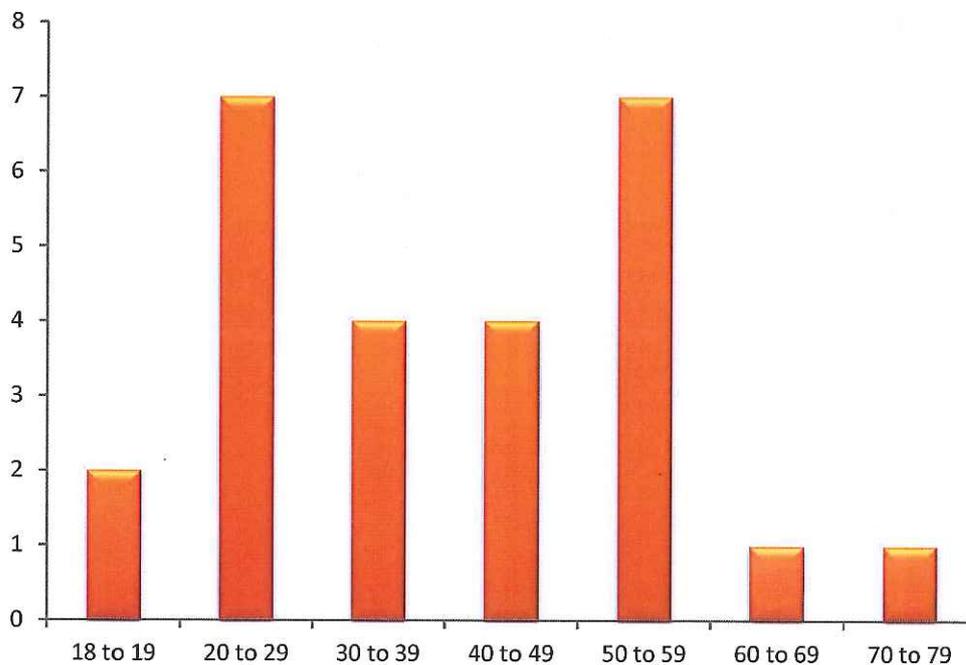
Twenty-six people who had a brain injury, intellectual disability, autism or a neurological disease affecting decision making, signed agreements with supporters. Fifty-two people had considered supported decision making, and even more had sought information. The fact that less than half proceeded to an agreement is unremarkable, because some people were isolated and did not have a family member or friend who could act as a supporter, and others were at the centre of significant conflict among family and friends.

Recruitment initially was through referrals from disability services and the Office of the Public Advocate itself. At the beginning, there were 16 referrals from non-government agencies, and up to 13 referrals from government agencies for a possible group of 10 in the first phase of the project (Wallace, 2012).

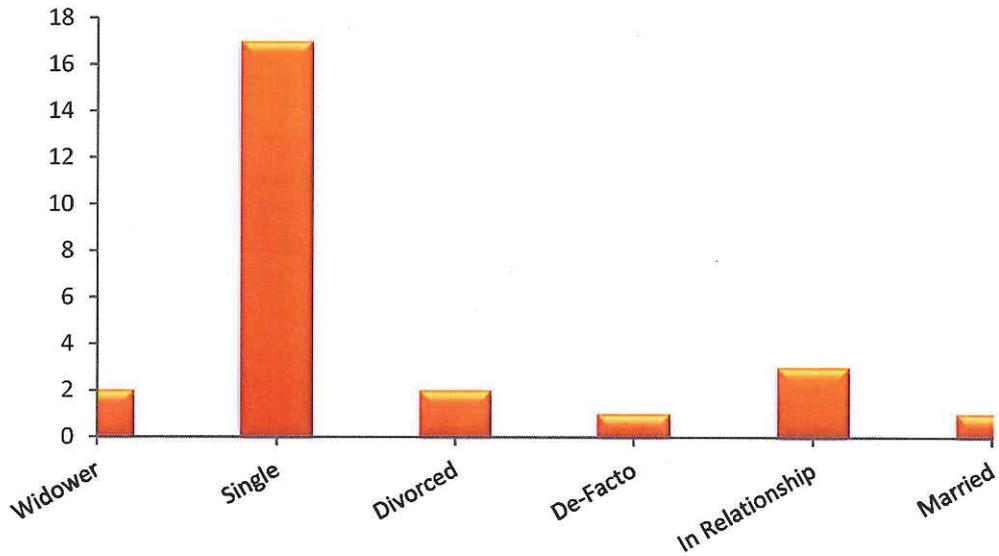
As the project expanded, people requiring early intervention were directly recruited through approaches to disability organisations. In essence, having been provided with information about the project and what it sought to do, people self-referred.

Descriptive statistics initially prepared for the 2012 International Guardianship Conference by Cher Nicholson, Senior Practitioner and Project Officer for the Supported Decision Making Project, provide a further breakdown of the overall study population. (Ms Nicholson was the practitioner who assisted the participants first to establish and then use their agreements.)

The project engaged a wide range of adult participants, from young people still in school to older people living in residential aged care. The majority of participants were not in a relationship. Details of the age and relationship status of participants are illustrated below.

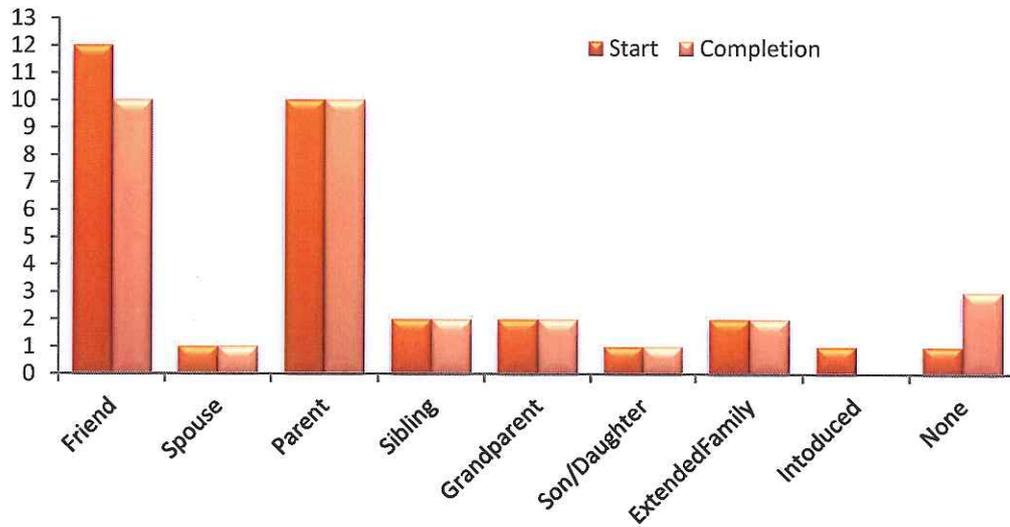


Supported Decision Making Project. Age of Participants.



Supported Decision Making Project. Relationship Status of Participants

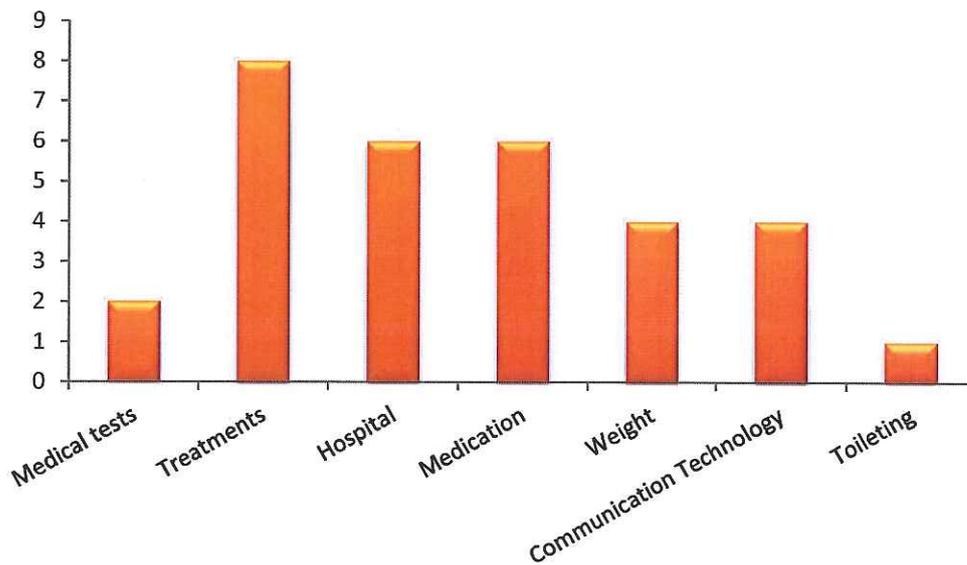
Supporters were evenly mixed between friends and a range of immediate family members. The graph below records that one person had no supporter. In this situation, the arrangement with the person's intended supporter fell through prior to commencing an agreement, so a volunteer supporter was introduced. The volunteer was unable to offer the time required, and so the project facilitator continued to offer decision support. (This was not part of the intended model for our practitioner to provide this support but it was necessary in the circumstances and data are included here for completeness.) It was possible for supporters to change during the life of the agreement. This chart describes the source of supporters, both at the beginning and at the completion of the period of the agreement.



Relationship between supported people and their supporters.

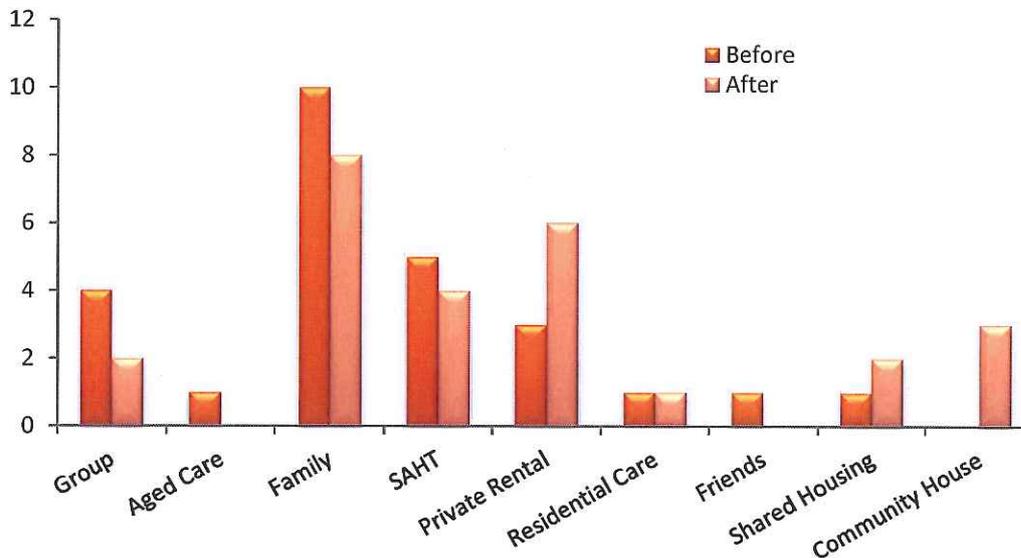
This trial considered healthcare, accommodation and lifestyle decisions.

Below is a breakdown of the health-related decisions made by participants. Because each participant made more than one decision, often across domains, the total number of decisions is greater than the number of participants.



Healthcare decisions made by participants in the Supported Decision Making Trial

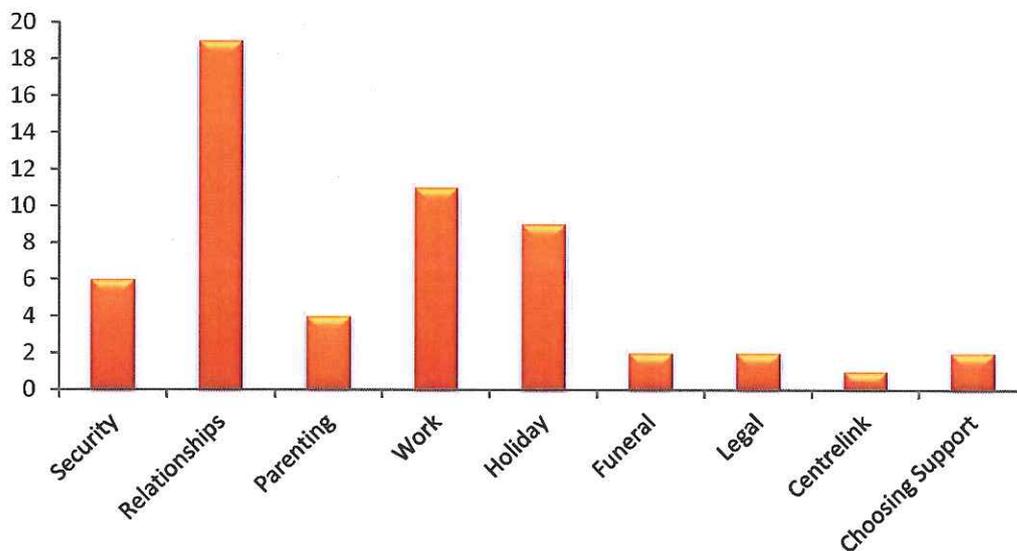
With respect to accommodation decisions, this is reflected in the changed accommodation circumstances of participants during the period of their agreement. The most notable decisions involved moves to independent accommodation with visiting disability supports. This is referred here as a 'community house', and is distinct from group home accommodation.



Changes in accommodation of participants in the Supported Decision Making trial.

Lifestyle decisions are listed below. Decisions about relationships, work and holidays were the most common lifestyle decisions made.

Breakdown of lifestyle decisions made as part of the Supported Decision Making Trial.



Outcomes of the South Australian Supported Decision Making Project

The evaluator of the project, Margaret Wallace, reported that the project had delivered specific benefits to most of the participants. Benefits included increased confidence in themselves and in their decision making. There was a growth in support networks, a feeling of greater control in the persons' lives, and increased community engagement. Supporters also reported benefits (Wallace, 2012).

Wallace (2012, p.5) reported that "the evaluation gives evidence that Supported Decision Making was both a companion process and viable alternative to substitute decision making for participants who were initially on guardianship orders."

The evaluator collected qualitative data and used quantitative data collected by the project coordinator. She interviewed 53% of participants, 27% of supporters, and staff from three service-provider organisations.

Views of participants and service providers

The interviews revealed increased confidence, decision making skills and personal empowerment.

I make my own decisions, using pros and cons. [It is] useful with my mother. The process is working with my mum. It's different. We never talked this way before.

I have confidence to make decisions, even if [it is a] mistake.

I thought decision making would help me. I needed something to help me instead of other people making decisions for me. I like to make my own decisions on my future.

I now have people who understand, recognise and appreciate what I say and how I do things.

I have a voice, a powerful voice because of [the Agreement]. I don't have to wait on or look to other people to make the decisions.

My kids have noticed a big difference in me. [My daughter] said she is so proud of me. It made me cry.

I get my independence. I think for myself — I feel good about making decisions. It's my new life. [I have] confidence in myself that I never had before. I didn't used to speak my opinions.

However, there were problems for participants related to access to money required to achieve goals. Two people reported a mismatch between their goals and the decisions of administrators who controlled their funds, although the situation eventually changed for them.

Wallace's report (2012) describes positive observations from carers.

With respect to service providers, one reported a positive experience with a client, and another organisation with three participants in the project also had clients who derived benefit from the experience. One client was able to negotiate successfully with his family for financial independence and another used the agreement to develop a healthcare plan.

A state government agency had a mixed experience. One client had a very positive experience. Wallace (2012) reported that the workers noted that a "...a particular strength of the process from their point of view was that the SDM (supported decision making) agreement gave the participant 'formal approval, a piece of paper, that said somebody is going to listen to me...it restores power'. However, two other people had not had a successful referral. The situation of people who were unable to participate is discussed in the next section.

Non-participants

Wallace (2012) reported that the workers, who had two referrals that did not proceed, suggested that: the vulnerability indicators that they use in their work to decide on required levels of support should be included in any decision for a person to be referred for supported decision making; and that a future program would benefit from tighter eligibility criteria to reduce inappropriate referrals.

Wallace interviewed four non-participants in the project. One wanted to be involved in the project but her brother did not agree to her request to be a supporter. Two others thought in retrospect that they did not need it. Another could not get a parent to agree. The person with a disability in this case had attended meetings with our project coordinator at an employment service, which led to a complaint to that service by the parent that the person with a disability should not be involved in activities without parental consent (Wallace, 2012).

Alternatives to Guardianship

The project design had two streams — an early intervention stream and an alternatives-to-guardianship stream. Wallace observed that the project infrastructure did not appear to be sufficiently developed to support the alternatives-to-guardianship stream to its conclusion. She said this "...points to the need for a considered process, within the processes and structures of guardianship to identify potential users of Supported Decision Making, and the need to clarify, at a public and formal level, the boundaries and intersections between Supported Decision Making and guardianship"(Wallace, 2012).

It is not possible yet to define the limits of supported decision making vs. guardianship in the population currently referred for guardianship. As indicated by the evaluator, some were organisational constraints. At the time that the Supported Decision Making Trial was underway, there was a major upsurge in guardianship appointments and demand for guardianship services. (The topic of the expanding application of guardianship was discussed in our 2011 Annual Report, p. 122.) Our intention to have advocates/guardians take on a number of supported decision-making clients as well as their guardianship was difficult to achieve in this context.

However, there were also other factors that may have limited the alternatives-to-guardianship stream. The guardianship clients were more frequently isolated and did not have family or friends who could act as supporters, compared to the early intervention stream. For this reason, ultimately, it will be necessary to have strategies to overcome this isolation — this might in the future come through the use of volunteer supporters to assist isolated clients or by linking supported decision-making initiatives to 'Circles of Support' that seek to connect people with disability to their community.

Also as analysed in our 2011 Annual Report, decisions relating to guardianship are not only made because of a person's impairment — often, other problems need to be solved. The person's own 'incapacity' may not be the real trigger for an order. It may be family incapacity to resolve conflict, a service incapacity to provide the necessary care and accommodation options, or a community incapacity to give at-risk people a right to safety from others through a range of adult protection and law enforcement strategies. All of these 'incapacities' can be addressed in ways that do not rely on removing a person's right to make personal decisions through guardianship, but supported decision making by itself may be insufficient. For these reasons, it would be wrong to expect that supported decision making alone can minimise guardianship, when other strategies are needed as well. (These other strategies may include offering mediation to resolve conflict, or providing better adult protection interventions.) This is further discussed in a recent conference presentation (Brayley, 2012) which argues that reduced reliance on guardianship will not necessarily occur through providing supported decision making alone, and will only be achieved by recognising the environmental issues affecting people; the solution requires addressing all parts of the UNCRPD, not just Article 12 related to decision making.

However, the evaluator did conclude that the project demonstrated that with clear criteria "...supported decision making is a viable alternative to guardianship, and can build capacity to the extent that existing Guardianship Orders were revoked." In this context, it is reasonable that supported decision making should be considered as an option each and every time that guardianship is proposed for a person with a disability. The approach can also work when an order is in place, in preparation for seeking to have an order revoked.

Net widening?

This topic was not specifically addressed in the evaluation. As already mentioned in this discussion, this was a possibility raised in Carney's report (2012) that matters addressed informally are brought up a level or two, and it was a concern raised early in the project that we may be seeking to unnecessarily formalise existing informal arrangements that were working well.

However, it was clear from our project that these informal arrangements were often not working to the satisfaction of the person with disability or their family; and clients, family or friends wanted change. Also, the informal arrangements were in fact *more* restrictive than the supported decision-making intervention in many situations, because decisions were made informally on a substitute basis by others — by family, friends or service providers.

The development of increased confidence and decision making skills will have personal benefits in the immediate term but may also assist in the future. Often, when informal decision makers are no longer available such as when parents become aged or infirm, or the informal arrangements break down due to conflict, applications for guardianship are made. It is reasonable to predict that this is less likely, if it happens to people who have learned decision making skills through supported decision making, they will be better able to make decisions for themselves now and in the future.

Supported Decision Making in the Future as a Sustainable Option

In this section, it is relevant to discuss both national and South Australian developments.

There is now significant momentum to expand supported decision making in line with the UNCRPD Article 12.

This year, the Victorian Law Reform Commission released its final report reviewing that state's guardianship legislation. It recommended that supported decision making be incorporated into that state's legislation, and made detailed recommendations on the provisions required that would make it work (Victorian Law Reform Commission, 2012, Ch. 8). These provisions would allow for both financial and personal decisions through supported decision making, give recognition to supported decisions, and describe both the powers and responsibilities of supporters. The Commission also recommended that a network of volunteers be established to act as support to those people who do not have someone in their life who can take on this role.

In New South Wales, the Office of Ageing, Disability and Home Care, along with the Public Guardian and the NSW Trustee and Guardian are commencing their own trial. This work will incorporate financial decision making, which was not a component of the South Australian work, and is an important next step. The South Australian Public Advocate is a member of their Advisory Group.

Other work is underway in the ACT and Victoria.

In South Australia, the Committee has considered future sustainability of supported decision making now that the pilot has finished. There are two key elements. First, legislative reform that could underpin the wider use of supported decision-making arrangements in the community, as well as their application in situations where non-statutory arrangements are insufficient, such as when there is conflict present. A second key element would be the provision of a small supported decision-making facilitation service, similar to the service that was operated by our Office during this project.

Our Committee is now meeting to develop recommendations for reform that will be presented to the Attorney-General for consideration. Initial discussions suggest four changes to the *Guardianship and Administration Act 1993 (GAA)*. First would be the addition of a principle acknowledging that people should be supported to enable them to make decisions as long as they can, in line with a principle of the Advance Care Directives Bill 2012. This has not proved controversial when introduced as part of that Bill, so it should be accepted as a part of the GAA. Second, when the Guardianship Board is considering an order, it should consider first if people can be assisted or supported to make their own decisions. Third, a short additional section be added recognising supported decisions, and the responsibilities of supporters. It is hoped that recommendations to the Attorney-General by the Supported Decision Making Committee will be finalised in the first quarter of 2013. The fourth change would be the addition of another section recognising supported decision-making agreements and the roles of supporters.

With respect to facilitation services, the development of individualised funding at a state level, and then the NDIS nationally, present an opportunity to establish small, supported decision-making facilitation services. There will be some form of brokerage assistance offered to service

users and carers. While this will be generally useful for people with any disability, extra steps will be needed to ensure that people with a decision making disability can take maximum advantage of the choice and control offered by the individualised funding model. Otherwise, individualised funding might empower the people around a person with a disability to make decisions on their behalf, but miss the opportunity to give power to the person with disability at every possible opportunity.

This Office has presented the need to have Supported Decision Making facilitation to the Minister for Disability and officials in the Department for Communities and Social Inclusion. There is currently significant interest and support for the goals of supported decision making that we hope might translate into the establishment of a small, sustainable Supported-Decision Making service in the future. The view of our Committee is that such a service would best sit in the non-government sector, but this would need to be with an organisation that does not already provide extensive disability services, as this could create a conflict of interest.

Supported Decision Making Committee

A Supported Decision Making Committee was established in February 2010.

It was formed under the provisions of the *Guardianship and Administration Act 1993 Section 21(3)*, 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.

A special acknowledgement of her work is due to Cher Nicholson, the Project Coordinator and Senior Practitioner, who filled a position funded through a grant by the Julia Farr MS McLeod Benevolent Foundation.

The membership of the Committee is as follows:

John Brayley

Chair

Robbi Williams

Graham Mylett

Tiffany Bartlett

Margi Charlesworth

Ian Cummins

Dell Stagg

Margaret Brown

Ian Bidmeade

Helen Mares

Julie-Anne Harris

Elly Nitschke

Di Chartres

In attendance

Cher Nicholson

*Senior Practitioner and Project Coordinator
Supported Decision Making Project*

Heather Linton

Volunteer

Margaret Wallace

Independent Evaluator

*External reviewer
and commentator*

*John Chesterman,
Manager Policy and Education
Victorian Office of the Public Advocate*

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.

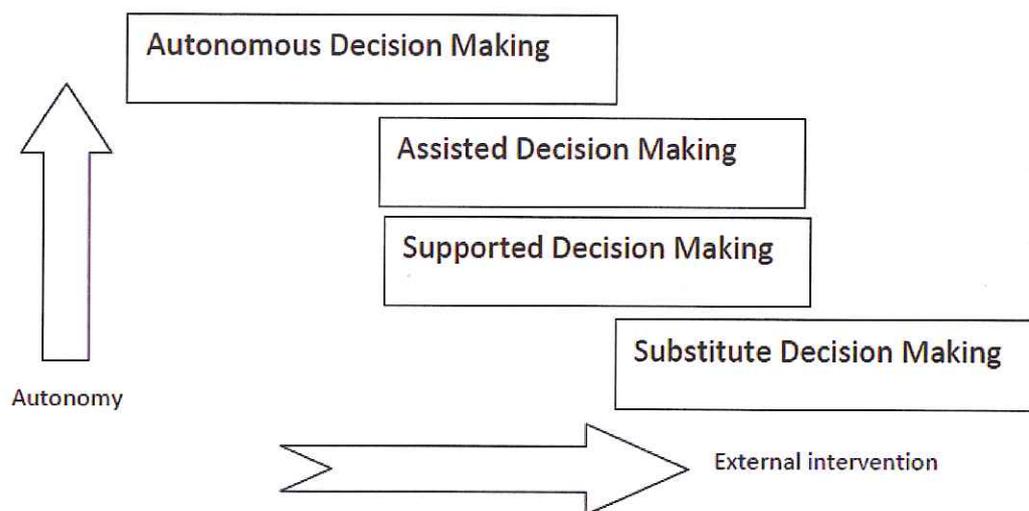


Figure A11: A simplified diagram illustrating the Stepped Model of Supported and Substitute Decision Making. Y-axis: increasing autonomy in a person’s life; X-axis, increasing intervention in the life of a person by others.

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.