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

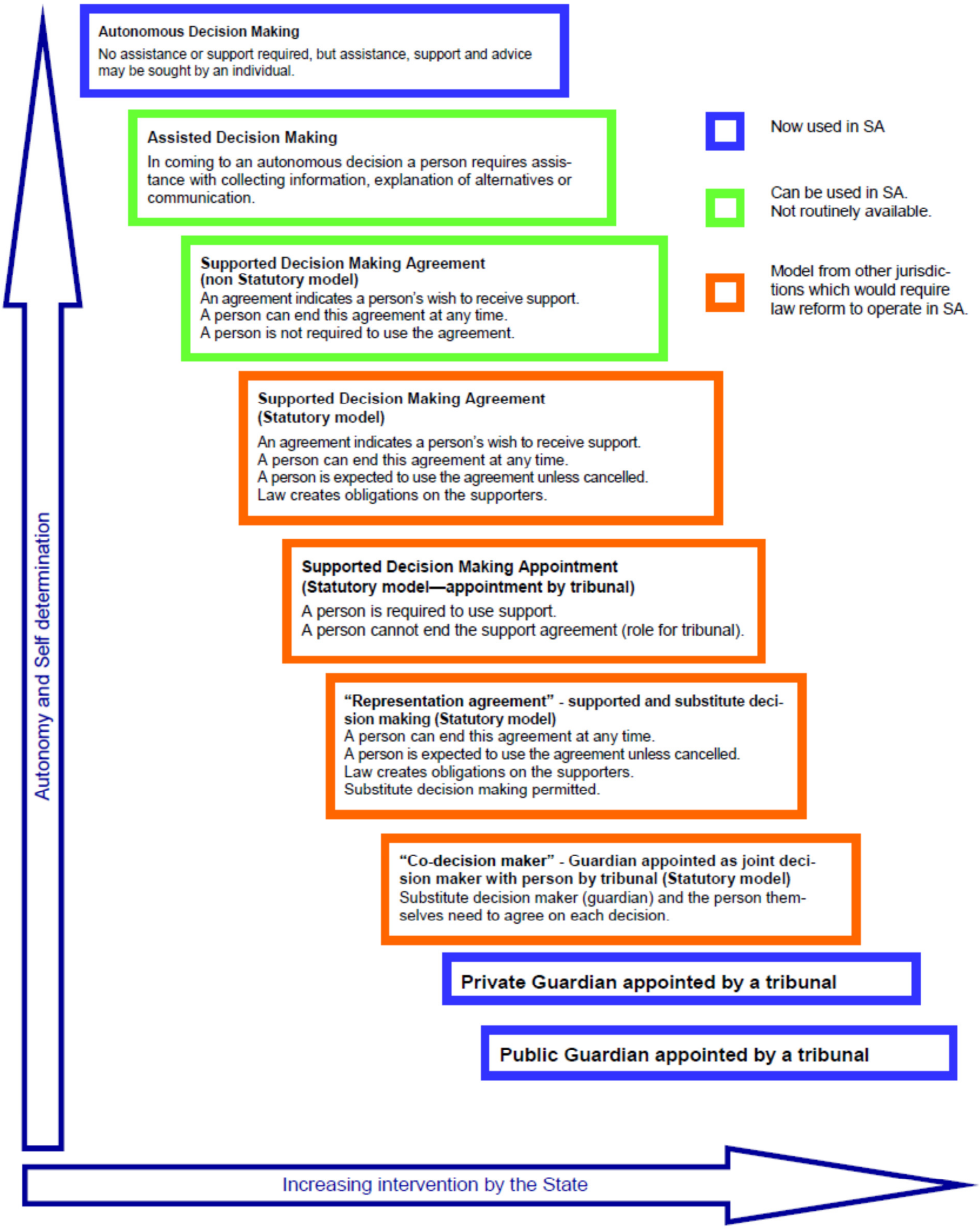
The South Australian trial involved setting up an agreement between a person with a disability and a family member or friend who would act as a decision supporter. It is a non-statutory model. Therefore, in looking at the successes of the trial, and also its weaknesses, it is important to acknowledge 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



Autonomous Decision Making
No assistance or support required, but assistance, support and advice may be sought by an individual.

Assisted Decision Making
In coming to an autonomous decision a person requires assistance with collecting information, explanation of alternatives or communication.

Supported Decision Making Agreement
(non Statutory model)
An agreement indicates a person's wish to receive support.
A person can end this agreement at any time.
A person is not required to use the agreement.

Supported Decision Making Agreement
(Statutory model)
An agreement indicates a person's wish to receive support.
A person can end this agreement at any time.
A person is expected to use the agreement unless cancelled.
Law creates obligations on the supporters.

Supported Decision Making Appointment
(Statutory model—appointment by tribunal)
A person is required to use support.
A person cannot end the support agreement (role for tribunal).

"Representation agreement" - **supported and substitute decision making (Statutory model)**
A person can end this agreement at any time.
A person is expected to use the agreement unless cancelled.
Law creates obligations on the supporters.
Substitute decision making permitted.

"Co-decision maker" - **Guardian appointed as joint decision maker with person by tribunal (Statutory model)**
Substitute decision maker (guardian) and the person themselves need to agree on each decision.

Private Guardian appointed by a tribunal

Public Guardian appointed by a tribunal

🟦 Now used in SA

🟩 Can be used in SA. Not routinely available.

🟧 Model from other jurisdictions which would require law reform to operate in SA.

Participants and Decisions Made

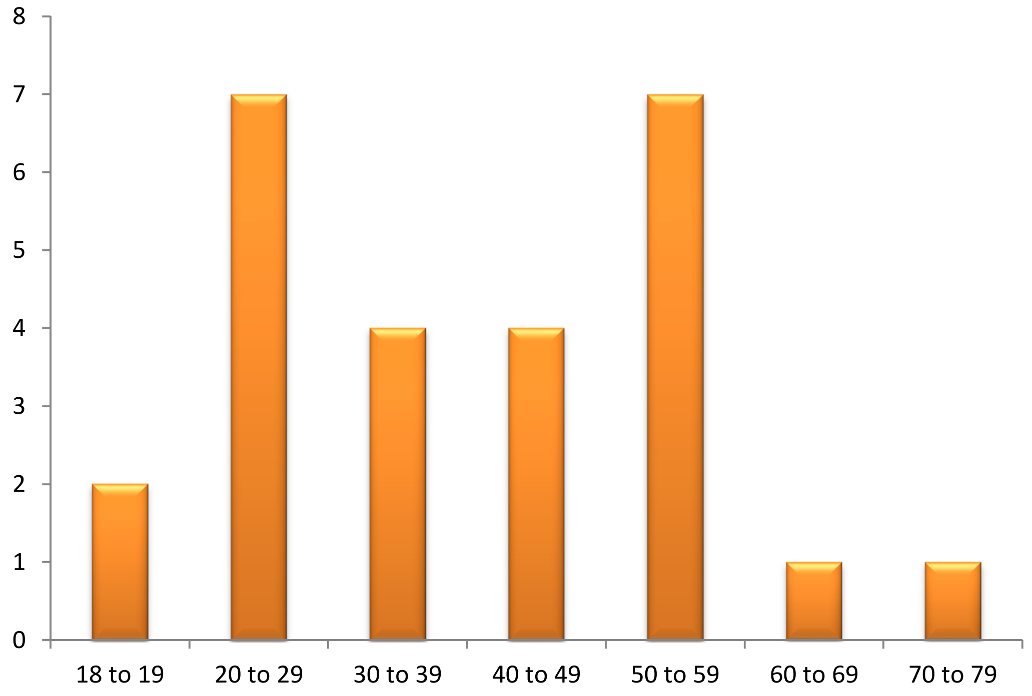
Twenty-six people who had a brain injury, intellectual disability, autism or a neurological disease affecting decision making, signed agreements with supporters. Fifty-two people had considered supported decision making, and even more had sought information. The fact that less than half proceeded to 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).

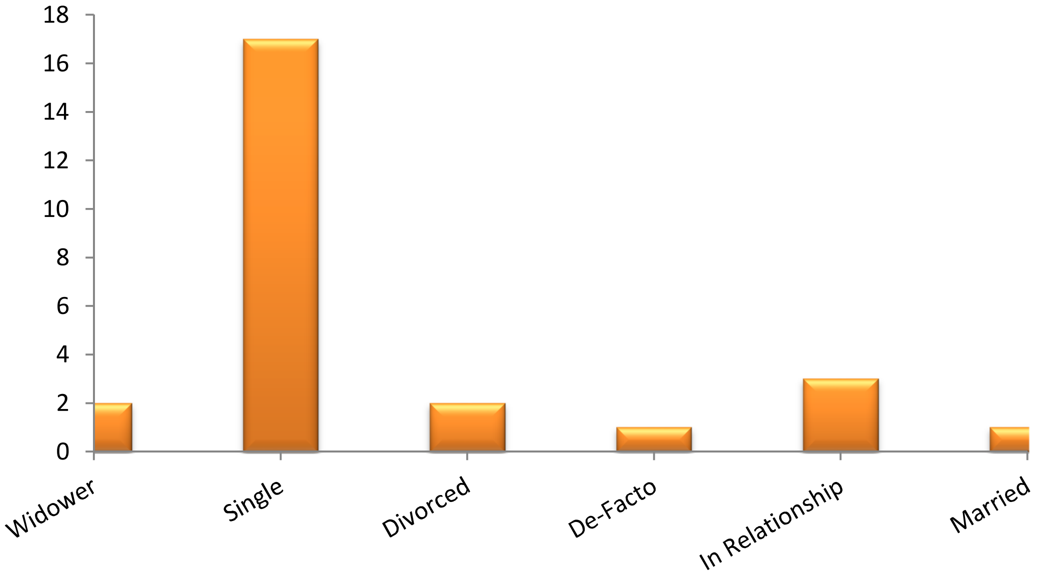
As the project expanded, people requiring early intervention were directly recruited through approaches to disability organisations. In essence, having been provided with information about the project and what it sought to do, people self-referred.

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.

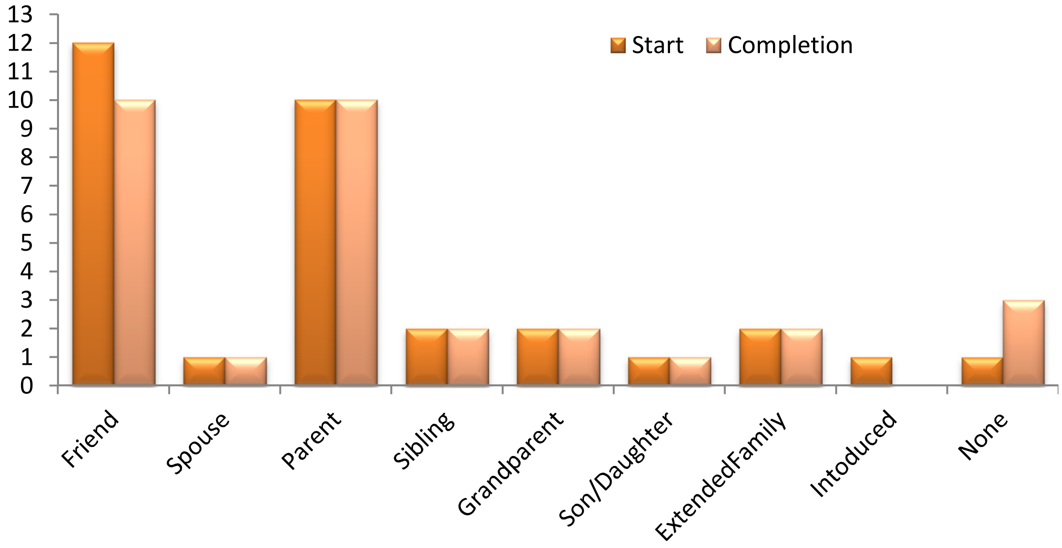


Supported Decision Making Project. Age of Participants.



Supported Decision Making Project. Relationship Status of Participants

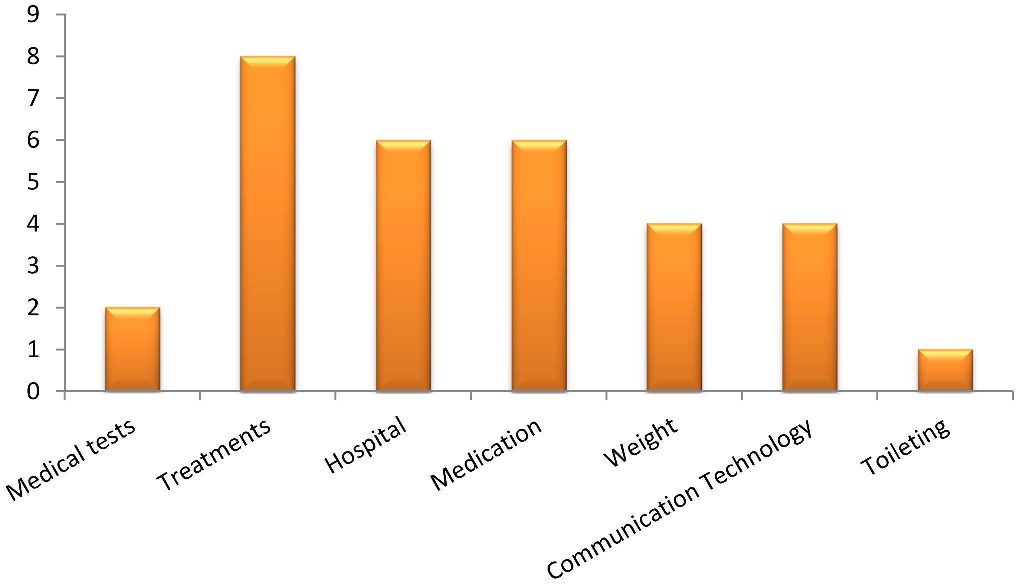
Supporters were evenly mixed between friends and a range of immediate family members. The graph below records that one person had no supporter. In this situation, the arrangement with the person's intended supporter fell through prior to commencing an agreement, so a volunteer supporter was introduced. 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.

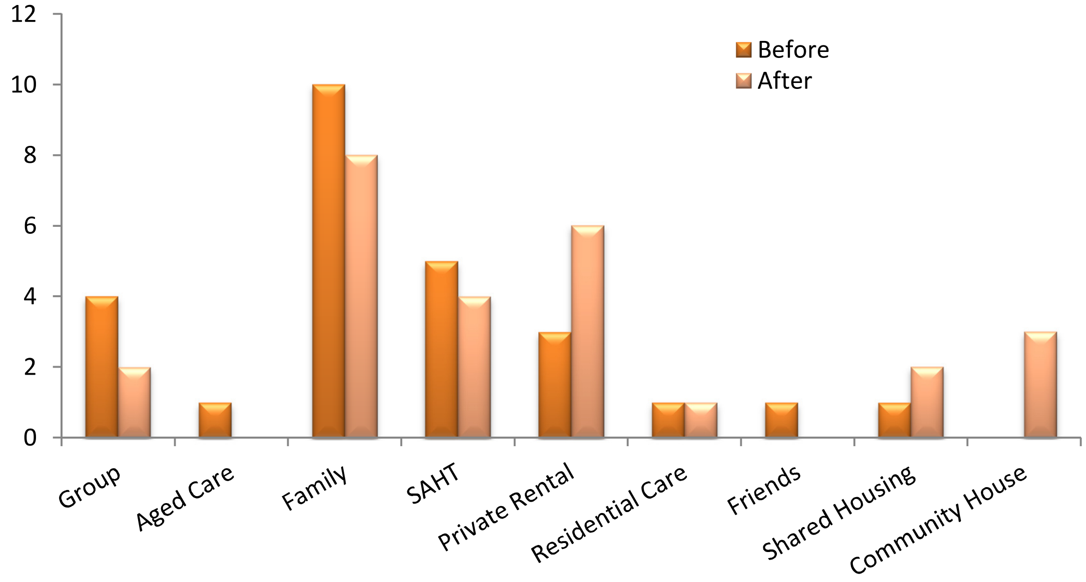
This trial considered healthcare, accommodation and lifestyle decisions.

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

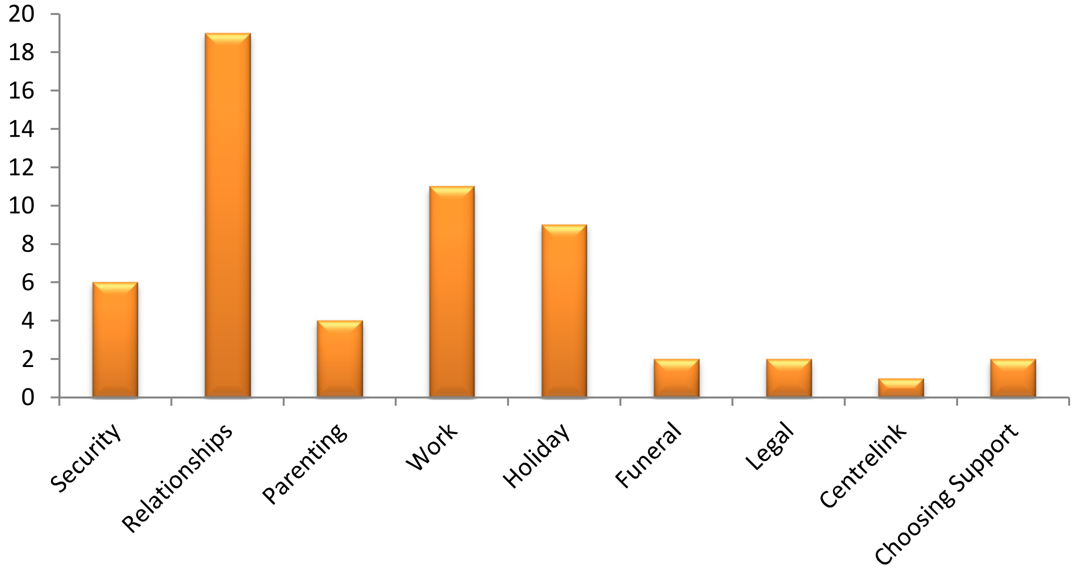
With respect to accommodation decisions, this is reflected in the changed accommodation circumstances of participants during the period of their agreement. The most notable decisions involved moves to independent accommodation with visiting disability supports. This is referred here as a 'community house',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