



South Australian Supported Decision Making Project Report of Preliminary “Phase I”

A preliminary “in house” evaluation of the process of establishing agreements

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Project Control Group :

The following people comprise the Project Control Group (in alphabetical order)

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Robbi Williams - Chief Executive of Julia Farr Association

Collectively the Project Control Group brings the following experience and expertise to the project: Four members of the project control group have a lived experience of disability. One member is the carer of a person with a disability. Members have experience in the law, social work, psychology, medicine, nursing, disability service reform, guardianship, quality improvement, counselling and academic research.

1 Executive Summary

The Supported Decision Making trial aims to assist people with a disability who need decision support to set up an agreement with people in their life, to provide this support, and to monitor the operation of the agreement. The model provides a “non-statutory supported decision making agreement”.

Phase I of this project is a small in-house evaluation to test the applicability of this approach.

The project has sought to set up agreements for people who have experienced either an acquired brain injury, autism, an intellectual disability, or a neurological disease affecting decision making.

Twenty two adults have been referred to the project, and eight have signed agreements. The agreements cover areas of health care, accommodation and lifestyle. Participants have also nominated specific areas in which they wish to receive support including personal care, diet, medical procedures, court matters, travel and the use of alcohol.

The commencement of the agreement has been a positive occasion for participants. Agreements have been used for decisions about surgery, general health care, smoking, friendships, housing and support services.

When asked participants positively reported on the information and education provided to them by the project facilitator.

During phase I the approach to “safeguarding” of participants from abuse was clarified by the project control group. Strategies are based on Article 16 of the UN Convention – Freedom from Exploitation, Violence and Abuse. This Article provides a right to safety, which in this trial will be provided through information, education, reporting and access to assistance from both the monitor and facilitator.

This will be explained further in the information given to participants in phase II. The facilitator does not have a screening or approval function for choosing supporters or monitors, but instead assists the supported person to make their own choice. Assistance is provided to potential supporters and monitors to help them decide if they can take on this task. If the facilitator has professional misgivings about a proposed agreement, the facilitator can decline to endorse it.

An important conclusion from phase I is that supported decision making agreements can be effectively established, and used. Phase II will provide more information by increasing the numbers of people in the trial, and providing further longitudinal information about the use of agreements.

2 Introduction

Supported Decision Making aims to ensure that people who have a disability, and need support making decisions, can receive that support.

In contrast, in substitute decision making, another person makes decisions on behalf of the person who has a disability.

The United Nation Convention on the Rights of Persons with Disabilities requires state parties to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity (described in Article 12 Equal Recognition Before the Law).

Internationally there is a concern that in many situations people who have a disability may have substitutes appointed as guardians for lack of appropriate support arrangements, that might allow a person to make decisions themselves.

The Office of the Public Advocate in partnership and with funding from the Julia Farr Association MS McLeod Benevolent Fund, is implementing a new model of service delivery to facilitate supported decision making arrangements, consistent with Article 12 of the UN Convention.

On the 3rd December 2010 the SA Health Human Research Ethics Committee gave approval for the South Australian Supported Decision Making Project Control Group to commence phase I of this trial (Trial approval number 421/11/2013). The trial is based in the Office of the Public Advocate and is a collaboration between this office and the Julia Farr MS McLeod Benevolent Fund.

The Summary of the Trial and the purpose of Phase I and Phase II was explained in the HREC application as follows:

Phase One (the preliminary trial) seeks to undertake a small scale in house qualitative evaluation that will test the applicability and assist the refinement of the service delivery approach to be used in Phase Two.

The trial proper (Phase Two) will be independently evaluated by a provider to be contracted through a tender process concluding early 2011 and will be subject to a further HREC application at that time.

Our group has undertaken this “in house” evaluation. It describes further developments to our service delivery model, and the testing of educational and other material.

Ms Margaret Wallace, of Muirgen Nominees has now been appointed as an independent evaluator for the trial proper – “phase II”. An updated ethics committee application will be submitted incorporating the changes in the service delivery model developed in phase I, along with the details of the independent evaluation.

3 Method

3.1 Aims of the trial

The Aims of the trial are

- to develop effective ways of enabling people to make supported decisions within an appropriate safeguarding framework
- to identify, facilitate and provide the range and forms of support that can make a difference
- to inform the principles for and a clear policy framework for supported decision making
- to develop practice guidelines for supported decision making
- to prioritise the voice of people living with disability about the optimal ways to provide support with decision making
- to promote awareness and strategies to assist agencies and service providers to work within a supported decision making framework with people living with disability so they can exercise their legal rights and capacity.

Supported Decision Making is being trialled as a new service delivery model – in this case the process of setting up supported decision making agreements, and supporting the participants to those agreements.

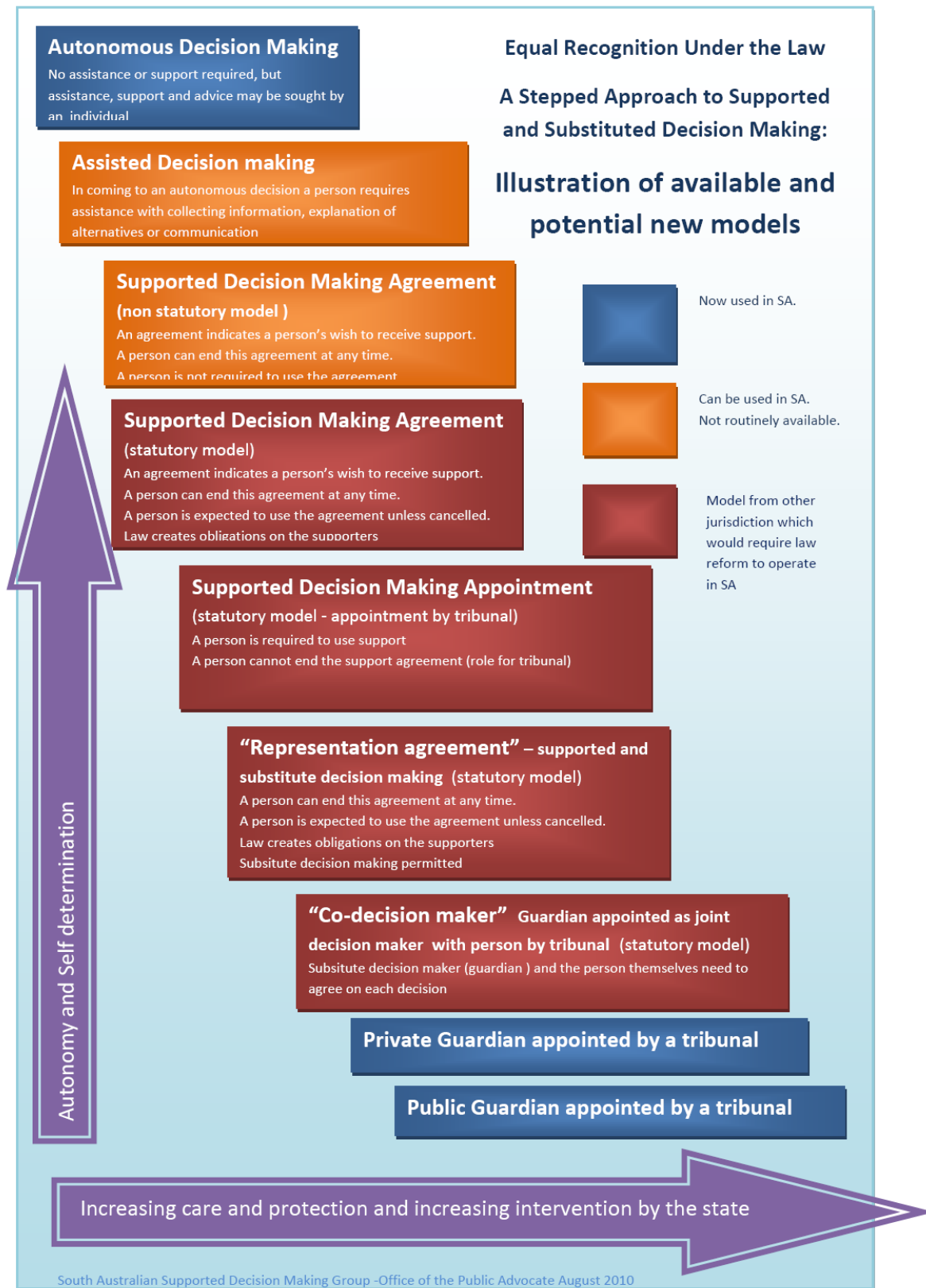
The model delivered is the facilitation of a non-statutory supported decision making agreement. This is one intervention in the spectrum of supported and substitute decision making which is illustrated on the next page.

Supported Decision Making will be offered to people who need support with decision making due to intellectual disability, autism, brain injury, or neurological disease .

The trial has two parts :

Alternative to Guardianship will offer supported decision making to a small number of people who might otherwise come under a guardianship order.

Early Intervention aimed at people who have a disability but the need for guardianship has not been considered. It can include people of any age who have recently experienced a brain injury or neurological disease affecting decision making as well as young people who have an intellectual disability or autism.



3.2 Participants and scope

3.2.1 Phase I: Number of Participants

Approval was obtained for 6-10 participants in phase I, along with relevant family, care providers, supporters and monitors. (It is anticipated that phase II will have 40 participants.)

3.2.2 Roles to be fulfilled

Below are the practical descriptions of each of the roles in the support relationship.

3.2.2.1 *The Supported Person:*

A supported person will need 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.

3.2.2.2 *The Supporter(s)*

Personal attributes:

- Respect and value the supported person's autonomy and dignity.
- Know the supported person's goals, values and preferences.
- Respect the individual decision making style of the supported person and recognise when and how support may be offered.
- 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.
- To be able to spend as much time as is required to support a person make each decision.
- *To form a trusting relationship with the supported person¹.*

Tasks to be undertaken:

- To recognise when a supported person may need to make a decision that requires support. This may be because support for a decision has been specifically requested by the supported person, or it may be part of the agreement for support to be routinely provided when certain types of decisions arise.
- To undertake research to assist the person make this decision (e.g. available options, potential outcomes)

¹ The requirement for the supporter to form a trusting relationship with the supported person was formally added prior to the commencement of phase II, however although not stated it was an implicit requirement in Phase I, given that the supported person is expected to have a trusting relationship with their supporter.

- To join the supported person at meetings with outside organizations set up to obtain information and explore options (for example; accommodation providers, employers, health professionals.)
- To assist the supported person analyse options by linking, where possible, the current decision to the person's values and preferences.
- To assist a person to identify similarities between a decision to be made now and past similar decisions that may assist with the current task.
- To assist the supported person to obtain advice from different sources, including providing, when relevant, the supporters own advice. (In which case it has to be clear that this is only advice, and should not overly influence the supported person's decision making.)
- To communicate the person's decision, and if necessary advocate for the implementation of the person's wishes.

3.2.2.3 Monitor:

A monitor will need similar personal attributes to a supporter.

Tasks to be undertaken:

- To be aware of all decisions made and how support is provided.
- To provide assistance to the supported person and supporter in undertaking the supported decision making process.
- To act as a resource for the other parties when a matter is difficult to resolve.
- To take necessary action if the monitor believes that the supported decision making agreement has broken down.

3.2.3 Phase I General Selection Criteria

Participants will need to have access to an existing network of informal supports or to the support of a community agency willing to develop these networks and trusting relationships where they are lacking. To ensure the project covers a range of circumstances, the project will endeavour to reach participants living at home with family, in a residential facility/nursing home or in the community, with or without paid carers.

Elderly people with advanced degenerative conditions have not been included in this particular trial, which has focussed on people who receive services from disability services. Also, families where there are allegations of abuse or high levels of conflict will not be included in this pilot project².

3.2.4 Types of decisions included

The South Australian Supported Decision Making Trial covers decisions in the areas of:

² This exclusion will not apply in Phase II – see discussion section.

Accommodation: for example the type of accommodation, location, whether to live alone or with others. This category may include decisions about supported accommodation offered by disability providers.

Lifestyle: Includes choosing who to spend time with and doing what activities. This includes choices of work, education and recreation. Lifestyle decisions include deciding which disability support services to request or accept, and where available enabled through self- managed funding to choose specific providers through self managed funding.

Health: consideration of advice from health professionals including choice of treatment options.

Specifically excluded from the trial are financial decisions, and decisions to take legal action. In the future a more comprehensive Supported Decision Making scheme would cover these areas. It is recognised that some areas of accommodation and lifestyle decision making will have a financial impact.

3.2.5 Phase I Decision Making Areas to be excluded

Specific decisions identified in the *Guardianship & Administration Act 1993* that require Guardianship Board approval will be excluded (ie selling property, ECT or sterilization). SDM will not be offered nor promoted as an alternative to financial administration, although it is recognised that where it is linked to lifestyle and accommodation decisions, it indirectly is related to SDM practice. Potential participants requiring decisions to be made only in these areas will therefore not be able to participate in this trial. .

3.3 Education and Information Material

A presentation about Supported Decision Making was delivered to providers and groups of people who have a lived experience of disability.

The projects practitioner met with individuals and their potential supporters and monitors who were referred to the project. Information about supported decision making was provided, and people were assisted to explore if Supported Decision Making would be the right choice for them.

Baseline data was collected (Appendix A). The information listed is based on the key pieces of information that would need to be discussed in helping a person decide whether or not to proceed with Supported Decision Making.

Potential participants were given written information which included information about the UN Convention, Supported Decision Making and the plain language information sheet approved for the research project (Appendix B).

Many of the potential participants were unable to read. Because of this the information sheet was converted into pictograms – a form of written communication taught in special schools. Potential subject were also provided a verbal explanation of the content of the information sheet.

For phase I because of the very small sample size qualitative feedback will be main source of evaluation data.

The baseline data collection has already been referred to (Appendix A). In addition it was planned to ask participants to undertake pre and post questionnaires. A questionnaire was developed (see Appendix C). Administering this questionnaire proved difficult as many of the initial participants could not read. For this reason the questionnaire will be re designed for phase II. When a person has limited literacy the practitioner or the evaluator will administer it verbally

Phase I had been set up evaluate the, initial process of education, and establishment of agreements, rather than their ongoing operation. It was planned to ask participants to complete personal journals – a “decision making diary” to list decisions made and issues that arose. Participants in phase I did not complete this task. Instead a number of participants would call the facilitator to discuss the decisions that were being made and the support given. The facilitator has been able to record information about the use of the agreements.

Nevertheless the idea of asking participants (supported people and/or supporters and monitors) to complete a diary – even a brief one – listing decisions made and the level of support given, is still considered a useful strategy by the project team. This diary keeping will assist with the evaluation, but hopefully also give a focus to participants to identify the times that supported decision making is practised, and how support has been provided. Rather than using a blank diary in phase II, decision sheets are being prepared that it is anticipated will assist participants to record their decisions.

3.4 Operation of the agreements

This evaluation has focussed on the establishment rather than the operation of the agreements.

The focus of the facilitator is to assist with the process of support, rather than with the actual decisions. It is expected that calls for coaching on either using support, providing support, or monitoring will be more frequent after the agreement has been implemented but will then taper off.

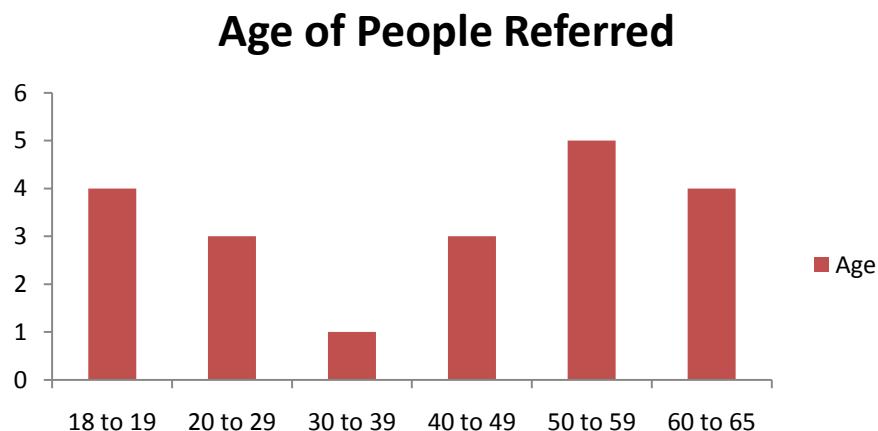
4 Findings

4.1 Description of participants

4.1.1 Potential participants who were referred to the program

Potential participants were referred from Disability SA, Brain Injury Network of South Australia, “Circle of Friends” (an organisation which develops social networks for people who have a disability and are isolated), the Disability Advocacy and Complaints South Australia, the Office of the Public Advocate and Special Needs Schools for people who have a disability.

The project facilitator has met with 22 people to provide individual information about the project. Ten were males, and 12 females. The age range is indicated below.

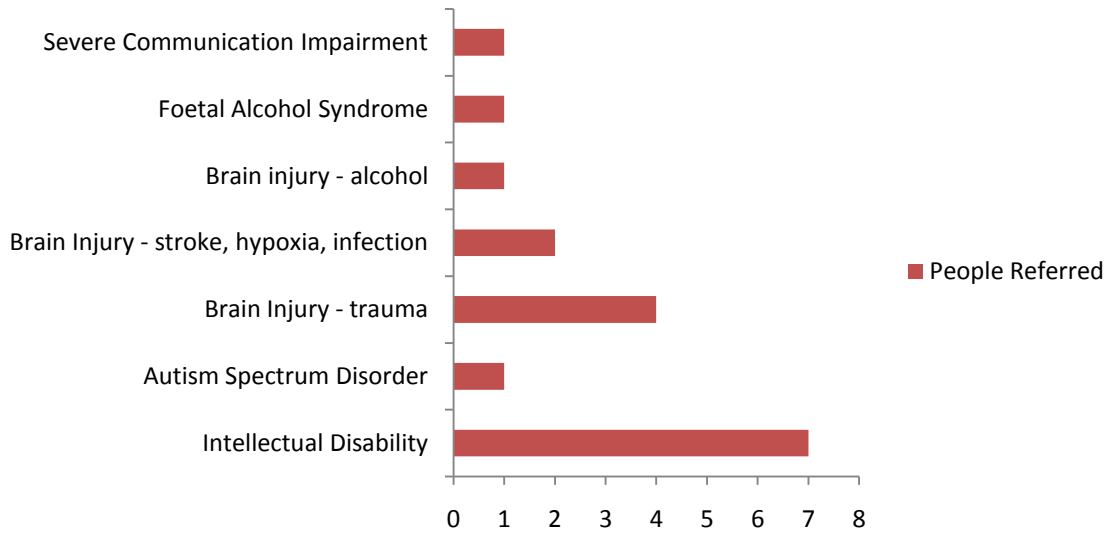


Four people aged 18 were referred.

The nature of the disability for 17 potential participants has been recorded, and is illustrated below.

The underlying conditions experienced by people referred to the program included autism spectrum disorders, stroke, brain injury, and one participant who had a profound communication disability due to advanced motor neurone disease. She had significant difficulty communicating her wishes, and service providers made many of her decisions. (Severe or profound communication difficulties can also lead to the appointment of a guardian.) .

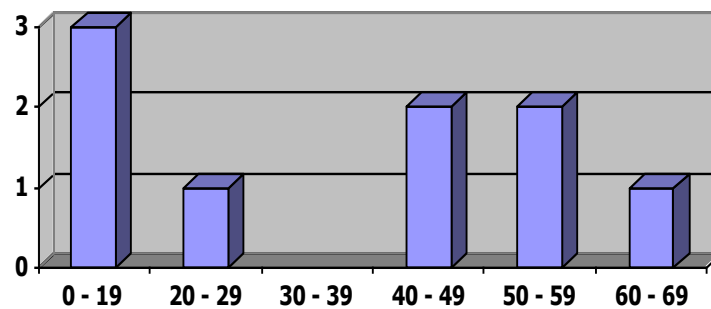
People Referred

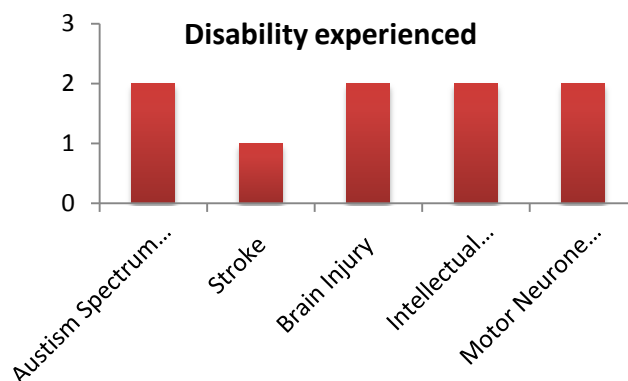


4.1.2 Participants who completed agreements

By the nature of this preliminary analysis, only small numbers (often just one subject) are in each group. Eight participants have completed an agreement, and one who is about to commence an agreement as of 30 May 2011. Of the eight there were 3 males and 5 females. The ages and underlying disabilities experienced are graphed below.

Participant Age Groupings





Supporters were either friends or family members (including two people who nominated spouses). Five people opted to have two supporters (eg a spouse and a relative.)

4.1.3 Participants who did not proceed to complete agreements

The facilitator has provided information about supported decision making to 22 people at this stage. In all cases service providers had referred potential participants. It was inevitable then that as potential participants were given more information about supported decision making that some would see the benefit of it, and others would choose not to proceed.

The final acceptance rate is yet to be determined because some people who have not signed an agreement, are still considering the option, and are aware that it is the intention of the project to continue into phase II.

Reasons for not proceeding include: non-availability of a supporter and not seeing the need for an agreement as existing arrangements have been satisfactory.

Three potential supported participants, who were themselves keen to participate and were considered by the project facilitator as people who would benefit from supported decision making, were unable to find supporters. It was not possible to identify family or of friends who might wish to take on this role. In two cases former support workers were suggested because of the belief that the support workers were now friends, but in both cases the support worker declined to take a role in this trial.

This is indicative of the social isolation experienced by many people who have a significant disability who may only have service providers and other people who experience a disability they meet through services in their network.

This led to a proposal to consider seeking volunteer supporters from service clubs to take on this role.

4.2 Agreements

As of 30 May 2011, 8 agreements have been completed. A 9th person is about to sign an agreement.

4.2.1 Agreement document

This project uses a non-statutory model of supported decision making. The agreements has no specific legal recognition.

The purpose of the document is to indicate the wish of the supported person to receive support, and the preparedness of the supporter and the monitor to give the support (or monitoring assistance).

In this context an agreement was developed which has been used in the initial agreements. A copy of the template agreement is attached in Appendix D.

4.2.2 Content of agreements

Participants could choose options from the template agreement and add additional items. Below are summarised the items chosen and added under each of the key statements.

The participants' accommodation has been listed to show any correlation of living arrangements with the decisions made and if needed support is influenced by those living arrangements.

4.2.2.1 How supported persons wanted supported delivered

The form contained the following items. All items were selected by participants:

I want my supporters to assist me to make my decisions by:

- Providing information in a way I can understand.
- Discussing the good things and bad things that could happen.
- Expressing my wishes to other people.

Participants added the following -

I want my supporters to assist me to make my decisions by:

- | | |
|---|----------------------|
| • Listening to me first and try and understand | (Home with family) |
| • Remind me to look forward and think of the future | (Home with family) |
| • Support with specific information re Court | (Sharing house temp) |
| • Support with responsibilities / advice | (Sharing house temp) |
| • Sometimes helping me to communicate | (Residential) |

4.2.2.2 Which decisions supported persons wanted support for

The form contained the following items. Once again all items were selected by participants:

I trust them to help me make decisions about: -

- Where I live
- Who I spend time with
- What to do with work/study/activities

- My health

All seven participants ticked agreement to all options.

Participants added the following -

I trust them to help me make decisions about.

- | | |
|---|------------------------------------|
| • Alcohol use | (Aged care facility) |
| • Travel | (Aged care facility) |
| • Spending time with the family | (Aged care facility) |
| • Parenting of daughter | (Independent living private house) |
| • Parenting of son | (Private house sharing temp) |
| • Court proceedings | (Private house sharing temp) |
| • Choosing my friends | (Residential setting) |
| • My health including all medical procedures | (Residential setting) |
| • Choice of diet | (Residential setting) |
| • Managing my personal care | (Residential setting) |
| • Managing medication including never having flu injections | (Residential setting) |
| • Support with decisions around access with children | (Lives alone private) |
| • Funeral arrangements | (Lives alone private) |
| • Parenting of daughter and decisions | (Home with family) |

4.2.3 Observations about the content of agreements

Our SDM facilitator noted that people living in residential settings nominated basic needs in a very specific way in their agreement. These were added these to the standard agreement items that refer to health, accommodation, lifestyle and relationships.

The draft agreement nominated how decision support might be delivered – obtaining information, discussing the “good and bad things” that can happen, and expressing decisions to others. Our facilitator considered that participants understood each of these roles, and there was not a need for additional items to be added.

On some occasions disability workers insisted on being present when the agreement was developed. Worker prompted the two specific additions to agreement made by people living with family (listening to me first, and reminding me to look forward in the future).

In phase II disability workers will not be present for key discussions unless it is a specific request made by other participants.

As might be expected additions were also prompted by upcoming events. One participant wanted support for decisions involving a pending court appearance. He had been homeless just prior to making this agreement.

The one person who required support with communication did not have speech until recently although had been assisted by a medication that aided her speech at some times of the day. Interestingly, she is also the one of the participants living in a residential setting who added many basic and very specific additions to the list of what she wanted to be able to make decisions about.

4.3 Observations on the signing of the agreements

The facilitator reported a number of occasions where the signing of the agreement was a significant positive life event for the person who would be receiving support.

Participants were pleased to have the agreements in place, and one remarked that this had been the first time in a long time that anyone had expressed confidence in her as a person to make decisions.

Supported Decision Making is inherently “strengths based” as it seeks to identify and support personal strengths rather than focussing on deficits and gaps. This can be a different experience for people who have previously lost confidence themselves in their ability to make decisions.

4.4 Observations of the initial operation of agreements

The purpose of phase I was to undertake a preliminary evaluation of the setting up of agreements, rather than evaluate their use.

Nevertheless it has been possible to make give some preliminary observations of when agreements have been used, as well as when they have not.

Our project facilitator has observed that already participants have expressed greater feelings of control and power in their lives.

Participants have already used their agreements to get support for decisions about surgery consent, health care, relationships, living arrangements and decisions about recreational activities. One person decided to stop smoking using the process, and also has put some boundaries around a relationship where alcohol was being destructive.

Another participant showed the agreement to her surgeon before surgery and he honoured her wishes to proceed. Yet another participant had an admission to hospital and also used it for health decisions and was thinking about formalising her wishes in an Advance Directive to be used if her condition

deteriorated further and she could no longer use the supported decision making process. This participant has since died. She had used the agreement process for decisions on tests, medication and other intrusive medical decisions. Just before she died her supporters used the process to aid her with decisions around her wishes for her funeral. This participant's family network for this participant expressed that described how this process gave the participant her much personal power and satisfaction before her death.

Two participants with agreements made decisions without using the agreed process. One absconded from his current accommodation after he agreed to use the agreement to make any changes in his accommodation. His supporters pointed out to him how he should and could use the process. Our facilitator considers that having had this experience of not using the process, he is now committed to using the process in the future.

Supporters have not managed to keep diaries and therefore it has been up to either the monitor or facilitator to track when supported decision making is being used, the decisions that people are making and the how they came to that decision.

4.5 Feedback from Supported Persons, Supporters and Monitors on the Work of the Facilitator

As part of the preliminary evaluation, the facilitator telephoned participants to ask questions about the information and education provided.

A list of questions is listed in Appendix E.

It is acknowledged that such an internal survey will have limitations – in particular it can be difficult for people to raise problems when the survey is not independently delivered, and in this case our facilitator who delivered the service also conducted the telephone survey. Participants were given the option to speak with another person if they wished.

Nevertheless the results can be indicative, and assist in developing material.

The phase II evaluation will use an independent evaluation, and therefore independent interviewer.

4.5.1 Telephone interviews of people participant receiving support

The summary of phone calls made to the 9 participants who will receive support from an agreement were summarised as follow (8 agreements completed and a ninth about to be signed):

- All said the written information was helpful, however only three of the nine went back to read it afterwards, and one read it again with help. When relevant the pictograms were also useful (this was only applicable to one of the participant, although other potential participants in the referred group had been able to make use of the pictograms). (The topic of literacy has been raised earlier, and the facilitator is also considering developing a CD audio version of the information.)
- All found the interview process comfortable
- All found the interviewer listened understood and treated them with respect and dignity

- Instructions were clear
- All were given the opportunity to speak by themselves.

It should be noted that most answers to telephone questions from people receiving support were either yes or no with little elaboration.

4.5.2 Telephone interviews of supporters

Telephone calls supporters were summarised as follows. (Five participants nominated two supporters, so for this reason, the total number of supporters contacted in this section was 12)

- All found the written information helpful. 8 of the 12 people had not heard of supported decision making prior to the project.
- Roles were clearly defined. Six participants said that roles were explained in a way that was easy to understand. One said no. Comments included “yes definitely” to “It took me a little while to understand it.”
- Clarification and questions were dealt with to their satisfaction. One of the supporters who lived interstate who only received information by phone and e-mail regretted not being able to receive information face to face.
- In terms of wanting to spend more time on some matters, five were satisfied with the time spent, and one person wanted more time. Comments included “sufficient time”, “self explanatory” “I would have liked to have spent more time on family involvement.”
- Supporters felt understood and listened to. Information was generally considered easy to understand. Comments were positive – “Very, very easy”, “straightforward”. One respondent wondered whether other family members understood the information.”
- All parties were satisfied with the outcome of their interview. Questions were answered, roles were clearly explained, and people felt they could follow up afterwards.
- People reported that they were treated with respect and dignity. One respondent said while she felt definitely respected she went onto say “As a friend of somebody, it was strange to be drawn into an official role. Both with Police Checks and a formal role. It was very odd.”
- All appreciated the time and care taken with the process

5 Matters that arose in phase I that have led to suggested changes to the protocol for phase II

As a result of the experience from phase I the following changes will be incorporated in the protocol for phase II.

5.1 Refinements to the practice of Supported Decision Making

5.1.1 Rights as a client of the Office of the Public Advocate

Participants in the trial become clients of the Office of the Public Advocate. While the research protocol outlines to the participants' their rights in receiving this new intervention as part of the research trial, it became clear that a statement of generic rights as an Office of the Public Advocate client is also necessary and will now be provided as well.

This matter was a topic of discussion in the Project Control Group. A subgroup involving committee members Margaret Brown, Di Chartres, and the facilitator Cher Nicholson, met to work through what are generic rights that participants have as clients of the OPA and what is specific to the research protocol.

The OPA generic statement will include; rights to confidentiality (including an explanation of generic mandatory reporting obligations in areas such as child protection and firearms possession for people at risk) and standard information about complaints mechanisms. This will be provided at the first meeting with any person who expresses interest in the trial.

For clients who proceed with a Supported Decision Making agreement, consent will be sought to share information with providers such as disability workers, and health staff. This consent will be limited to obtaining information that may assist the participants in their roles providing and receiving decision support, and giving information to the providers that may assist them in working with the supported person and their supporters .

In phase I as all referrals came from service providers, there was significant contact between those providers and the SDM facilitator. The new arrangements will codify the existing practice, and may also be helpful in phase II when the project will seek more self referrals direct from either the person with a disability or their families and friends.

Participants will be able to use other services provided by the Office of the Public Advocate, independent of their involvement in the Supported Decision Making trial. This includes the enquiry service or in some instances accessing an advocate or guardian.

One topic that arose was what the Office might do if a person wished to have Supported Decision Making but did not wish to participate in the research. We concluded that the Supported Decision Making project is a research intervention only at this time. The evaluation of this project can identify when an intervention is benefiting an individual as well as and the group as a whole. At this time the Office is not able to offer the intervention without this follow up evaluation.

5.1.2 The right to safety and the use of police checks

The Project Control Group was asked by the Human Research Ethics Committee to consider if police checks should be undertaken for all supporters, even if they are family members. This was a view presented for our consideration.

To assist the Project Control Group, Helen Mares (committee member and Assistant Public Advocate) developed a discussion paper that considered this issue. This paper addressed the risks and benefits of compulsory police checks to assist the Project Control Group. The paper outlined a procedure for undertaking police checks which included, keeping the results confidential, and only acting on the checks if necessary.

The majority of supporters were family members.

In at least two instances there were significant allegations made about the actions of two potential supporters.

In one situation allegations were unsubstantiated. The potential supporter was very keen to have a police check to clear their name. In the other situation when an allegation was confirmed, the police check was unnecessary. Both the supported person and the supporter realised that the agreement could not proceed under these circumstances.

Reactions to the police check varied from bringing it on because there was nothing to hide, to one of consternation that a person's trusting relationship and motivations for a friendship were being questioned.

This led to the Project Group considering a more fundamental question – who is actually deciding if supported decision making is appropriate, and who decides who the supporter should be? Is it the person with the disability, or is it the facilitator? Is the project assessment process at risk of becoming a screening mechanism similar in some ways to guardianship?

The Project Group acknowledged that there is potential for misuse of supported decision making arrangements. For example in guardianship practice, it is not uncommon to see evidence of the misuse of traditional legal advance directives such as Enduring Powers of Guardianship and Enduring Powers of Attorney. These documents in the wrong hands can become instruments of abuse. While these traditional legal documents give substitute powers rather than setting up a support arrangement, the potential risk for abuse in supported decision making arrangements is a reality.

In addressing this dilemma the Project Group returned to the UN Convention, which provides guidance on how autonomy can be protected, while safeguarding is also provided. With respect to the implementation of Article 12 the UN Enable website advises of the need for safeguards to these arrangements – “*so States must do what they can to support those individuals and introduce safeguards against abuse of that support.*”

Article 16 of the convention considers freedom from exploitation, violence and abuse. This provides a right to safety, and includes the provision information, education, reporting mechanism, and access to assistance as safety strategies.

This sets the context. It is the participant, not the facilitator, who makes the decisions. The facilitator assists the supported person in deciding who they want as their supporter. The facilitator can also assist the proposed supporter to decide if they can accept the invitation to take on such a role. For this trial the provision of a monitor, and ongoing access to the facilitator, provide additional safeguards.

So far this approach has covered all situations in this trial.

However should it ever be the case that a participant did want to proceed with an agreement that may put them at risk, then the facilitator, as the person providing a professional service, has the option to decline to provide the service that would establish such an agreement. No professional is under an obligation to provide a service if it will be harmful to a client.

At the conclusion of this discussion it was decided that

- The safeguarding strategies of the project will be based on the UN Convention which defines a right to safety.
- The decision to proceed with an agreement is ultimately one for the participants, and the supported person in particular, and not for the project facilitator. The facilitator does not have a screening or approval function.
- The role of the facilitator is to help the participants make these decisions in an informed way. (Given that supported decision making is a new concept this is part of the education role of the facilitator).
- Should participants wish to proceed with an agreement that the facilitator has professional misgivings about, the facilitator can decline to proceed.

In phase II this facilitation role will be explained in more detail in the information sheet about the project.

In phase II it is proposed that the use of police checks will be modified. in the following way:

- When the supported person already knows a potential supporter, police checks will not be routinely requested.
- Police checks will not be undertaken on family members as is the case now.
- However unlike in phase I, police checks will not be undertaken routinely on friends outside the family. (as occurred in Phase I)
- When allegation have been made against a potential supporter, that the person denies, the facilitator may then assist the supporter obtain information that clarifies the matter. This may include a police check, or the outcome of investigations undertaken by other agencies.

- As noted earlier in this document there is a plan for the project to introduce community volunteers to people who are isolated and do not have existing potential supporters. In this situation, all volunteers will be required to have both references and police checks.

5.1.3 Inclusion when there are allegations of abuse or where family conflict exists

Further to the previous discussion, the phase I exclusion of participants who were the subject of allegations of abuse, when these allegations do not involve prospective supporters or monitors is difficult to justify.

Clearly if the allegation of abuse is directed at the person who has been nominated as a supporter or a monitor, then this is a significant issue to be resolved.

However because abuse and exploitation are experiences that are more common for people who have a disability than the general population, people may be unnecessarily excluded from an intervention that may assist with taking back control of life and stopping abuse and neglect.

Similarly family conflict can be common. Even when one family member may be in conflict with another family member who takes on the support role, it may still be possible for all involved to recognise the validity of the support role.

It is possible in the presence of conflict that an effective support arrangement may lead to better consistency in decisions. The decisions belong to the person themselves, rather than having different family members making different informal substitute decisions at different times.

5.1.4 Small trial of volunteer supporters

In phase I there were three people who were unable to proceed with an agreement because of isolation and lacking supporters.

The facilitator was concerned that people in this situation who are keen to participate in supported decision making might miss out. The suggestion was to engage volunteers from local service clubs.

Phase I was limited to people who “have access to an existing network of informal supports or to the support of a community agency willing to develop these networks.” The latter included one person who was linked with such an agency.

The new proposal is for our program to develop these links.

The Project Control Group discussed this matter. Approval was given to seek permission as part of phase II for the three people already identified. This experience would then inform further decisions about potentially expanding this role.

5.1.5 Extension of program to people under guardianship

In phase I two people were referred to the program who were currently under a guardianship order.

In both cases it was desirable to trial supported decision making, to give the protected person practice in making decisions, with support even though the order was still in place.

The results of this experience will be presented to the Guardianship Board when the order is reviewed.

When a person is under guardianship, the final accountability for making a decision rests with the appointed guardian. For this reason a supported decision making arrangement can only be used to help a person formulate their expressed wish. It would be expected that an expressed wish formulated in such a way will have more weight when considered by a guardian.

The discussion on this topic highlighted that for any citizen the act of making a decision does not necessarily mean that the decision will be enacted. For a person under guardianship it may mean convincing the guardian. For a person not under guardianship there may be other barriers stopping a decision being implemented such as convincing third parties, or limitations on available options in accommodation and other areas.

5.2 Refinements to the process of the research trial

5.2.1 Exclusion of mental illness as a primary disability

The focus in phase I has been on assisting people who have needed support with decision making as they have experienced an intellectual disability, brain injury or neurological disease who have needed support with decision making .

People who have a primary mental illness have not been recruited. People with mental illness were included in the initial protocol, but participants were not recruited.

People who experience mental illness can benefit from supported decision making. The same principles can be applied, however the approach needs to be modified to respond to the needs of people who experience fluctuating capacity, and be considered in the context of the use of involuntary orders made under the Mental Health Act by mental health professionals as well as orders made by the Guardianship Board under the Guardianship and Administration Act. This project has focussed on engaging disability providers, rather than practitioners and providers in the mental health sector.

5.2.2 Potential participants who have not proceeded with supported decision making

In phase I consent for research was obtained at the time participants decided to proceed with the Supported Decision Making agreement.

The plan for phase II is to seek consent earlier – after the first interview – when people decide whether to continue seeking more information about the supported decision making project. This will allow consideration and documentation of the reasons why people have not proceeded with a Supported Decision Making agreement.

5.2.3 Development of a specific decision making diary

Participants in phase I have not completed this diary. The facilitator considered that it may be necessary to develop a more structured diary that can serve as a decision making aide, with prompts to list decisions and the factors considered in weighing up decisions.

So while this requirement has not been successful in phase I it will still be continued with modification.

5.2.4 External evaluation

The specific benefits of Supported Decision Making have been proposed in the five areas illustrated described on the next page.

This will be used to finalise the content of the external evaluation in phase II. Proposed Specific Benefits of Supported Decision Making for Adults Living with Disability

1. Adults living with disability (ALWD) <ul style="list-style-type: none">▪ Improved Self esteem▪ Confidence in decision making▪ Confidence in rights▪ Improved decision making skills▪ Increase in areas of decision making▪ Improved problem solving skills▪ Increase in support networks▪ Personal empowerment▪ Ease of transacting business on behalf of ALWD	2. Carers and decision making supporters <ul style="list-style-type: none">▪ Understanding of the rights of ALWD▪ ALWD exercising rights in greater range of areas▪ Adult to adult interaction is evident▪ ALWD have positive relationships with parents/carers▪ Decrease in substituted decision making▪ Ease of transacting business on behalf of ALWD
3. Wider Community <ul style="list-style-type: none">▪ ALWD's rights & personal choices upheld▪ Greater inclusion/participation in life of the community▪ Increased opportunities for personal decision making▪ Greater acceptance of ALWD's decisions▪ Less administrative / bureaucratic processes and interventions▪ Fostering of positive community attitudes towards ALWD	4. Service providers <ul style="list-style-type: none">▪ More person centred and accountability to the person living with disability▪ Increase in provider knowledge, skills and acceptance of supported decision making▪ Respectful of the wishes & personal choices of ALWD▪ More flexibility in provision of supports by providers
5. Systems (Given major systems change is unlikely until the trial is evaluated, our intention here is to assess progress towards, attitudinal change and internal OPA SDM systems) <ul style="list-style-type: none">▪ Policy changes, including more acceptance of SDM in existing processes and practices accepting of SDM▪ SDM best practice identified and in place▪ Tools and resources in place that facilitate supported decision making	

6 Conclusions

Phase I has been a preliminary trial to further develop the process of providing education, information, and assistance to people who are considering supported decision making.

These findings need to be interpreted within the caveat of the small numbers of people involved, and the use of an internal evaluation.

In conclusion

- The Supported Decision Making trial is effectively providing information about supported decision making, what it is, and how it might work.
- This information has enabled people with a disability, and their potential supporters and monitors to decide whether to proceed with an agreement.
- The facilitator's role is to assist participants in deciding if supported decision making is what they want and then be a resource to assist and coach participants and supporters in achieving their goal.
- The commencement of a supported decision making agreement can have a positive impact on a person's life. A "strengths based" approach can build confidence in decision making.
- The agreements when established have been used for a range of health care, accommodation and life style decisions.

Appendix A Baseline data for participants

Date seen

Name Date: of birth

Time Place:

Referred by:

Personal Details

Age

Sex

Address

Telephone number

Email:

Married, Single, in a relationship

Work, Day Options, None, Other

Pension, Salaried, Other

Nature of disability

Ethnicity

Guardianship order:

Living Arrangements; explore whether on own, with family, with staff, with casual paid support? with family support etc? Choose staff? choose who live with, share with? own bedroom? Own, rent, buying, provided by organisation? (Is lease with them or the organisation

Social and recreational activities

What activities do you do other than work, day program on week nights? weekends? Holidays?

Key relationships

Who are the most important people in your life? Why are they important?

How long have you known these people? How do you spend your time with them,

Mobility

How do you get around? If you need help who provides it?

Communication needs**Making YOUR OWN decisions**

What kind of decisions do you make on your own? Is this very often?

Do people ever change your decision? Why?

Do people listen to you when you make a decision? Does what you have decided happen?

When people HELP YOU to make decisions

Do you need help making decisions? Do you ask for help to make decisions? Who do you ask? Why? What kind of decisions do they help you to make? Lots of times or just occasionally? Do some people just help anyway? Do you make the decision or do they? Or sometimes do you just go along with what they say?

When people MAKE DECISIONS FOR YOU (or tell you what you can or can not do)

Do people ever make decisions for you without you asking them to?

Who makes these decisions?

Can you change the decisions they make? What kind of things do they make decisions about for you? Can you change the decisions they make? If no, why not?

Appendix B Information Sheet



About the Supported Decision Making Project



This project is for people who may need help with decision-making. This might be because the person has a brain injury, stroke, intellectual disability or other condition.

We invite you to join this project which is trying to show a new way to support people to make their own decisions.

The United Nations Convention on the Rights of Person's with Disabilities, says that people should make their own decisions wherever possible, and that if they need help, they should, get the support that they need to make decisions. The aim is to provide support, instead of appointing another person to make decisions for them.

You can join this project if:

You would like to receive support making decisions

You can indicate the decisions that you want help to make, on your own

You already have or can form a trusting relationship with another person who will support you - 'the supporter'

You feel able to stop the arrangement when and if you want it to end or to change your 'supporter'

The good things about being in this project will be:

You will get help in making decisions from people you trust and who know you.

Your wishes will not be ignored.

You will get help speaking up for your rights.

You may be able to avoid the government making decisions for you.

Some of the decisions you will be supported to make will be:

- ☐ **About taking care of yourself and your health** - going to the doctor or the dentist, arranging tests, deciding about medications, consenting to surgery.
- ☐ **About where you live and who you wish to live with-**
- ☐ **About your social and leisure activities** -what you want to do, when and who with
- ☐ **About your work, training and day options**
- ☐ **About your relationships** -who you want to spend time with

Choosing someone to support you

The person you choose to help you is called your supporter. This person helps you to make your own decisions. The supporter does not make decisions for you and cannot make things happen that you do not want.

As an adult no one has the right to make decisions for you. Sometimes you may need help making decisions and with saying what you want. Sometimes you might feel that you are not listened to and that others are making decisions for you.

Choosing a supporter and telling them in what areas they can help you make decisions can change this. This can be done by putting this in writing and if need be on video or a tape.

The Supporter

Your Supporter must be able to

- Respect you, your goals and wishes
- Agree to assist you to make your own decisions about what you think is best for you and not impose their own opinions or preferences if they are different to yours
- Spend time with you to find out about your wishes and support you make your decisions and if need be, tell the people who need to know about your decision.

Who can you choose as your supporter?

You can choose a spouse or partner, parent, family member or friend who is over age 18.

You can have more than one supporter. Sometimes people want a different person to help them make decisions about different things. It is a good idea to think of another person as well in case your first choice is not available when you need them.

If you join this project you will need to have a monitor

A monitor is someone other than your supporter who can help you make sure things are working well with your supporter.

This person can also be a trusted friend, a relative or someone else.

If you don't know anyone, you can ask for a staff member from the Office of the Public Advocate to be your monitor. This does not mean the monitor will make decisions for you.

If you join the project because someone else has been making decisions for you or who thinks that you need decisions made for you - the Office of the Public Advocate will give you an extra monitor. You will still be in charge of your decisions.

The Monitor

Your monitor is there to provide assistance if problems occur. If the support was breaking down a monitor would tell you, as well as informing us at the Office of the Public Advocate.

We want to find out if this project works

Your views are important and we want to hear them. An independent person will talk to you about what works well, what could be better and what you like or don't like about the project. You might get asked some questions more than once.

The project will be written up and the Public Advocate will mention it in his report to Parliament each year.

ARE YOU INTERESTED?

CONTACT.....Cher Nicholson
Project Coordinator and Senior Practitioner
Supported Decision Making Project
Office of the Public Advocate

Telephone 8342 8209

If you have concerns about the project contact the Executive Officer of the Human Research Ethics Committee.

Executive Officer, HREC
Research and Ethics Policy Unit
SA Health
Phone: (08) 8226 6367
Fax: (08) 8226 7088
Email: hrec@health.sa.gov.au

Appendix C: Questionnaire

A few questions about decision making

To be completed by a person receiving decision support

Supported Decision Making Project

1. I am confident to make decisions

Strongly disagree	Disagree	Neither agree or Disagree	Agree	Strongly agree

2. I have the skills needed to make decisions

Strongly disagree	Disagree	Neither agree or Disagree	Agree	Strongly agree

3. People close to me respect decisions that I make

Strongly disagree	Disagree	Neither agree or Disagree	Agree	Strongly agree

4. People close to me allow me to make my own decisions

Strongly disagree	Disagree	Neither agree or Disagree	Agree	Strongly agree

5. People close to me make decisions for me

Strongly disagree	Disagree	Neither agree or Disagree	Agree	Strongly agree

6. I am given the support I need to make decisions

Strongly disagree	Disagree	Neither agree or Disagree	Agree	Strongly agree

Date:

Appendix D: Template Agreement



SUPPORTED DECISION MAKING AGREEMENT

(Office of the Public Advocate SA 2010-2012)
Funding support from the Julia Farr MS McLeod Benevolent Fund



Date

I choose

.....
name, relationship

.....
name, relationship

to be my **supporter(s)** and assist me to make decisions.

I want my **supporter(s)** to assist me by *(for example)*

- ☐ Providing information in a way I can understand.
- ☐ Discussing the good things and the bad things that could happen.
- ☐ Expressing my wishes to other people
- ☐
- ☐
- ☐

I trust them to help me make decisions about:

I want my **supporter(s)** to assist me by *(for example)*

- ☐ Providing information in a way I can understand.
- ☐ Discussing the good things and the bad things that could happen.
- ☐ Expressing my wishes to other people
- ☐
- ☐
- ☐

I accept to be a **monitor** who will keep track of how things are going with my supported decision making.

I agree to be a supporter and assist make his/her own decisions when he/she asks me to.

I agree to monitor supported decision making by and let the Supported Decision Making Project Co-ordinator know how things are going.

We will review this agreement by
month and year

Any person in this agreement can stop being involved in the agreement by letting the Supported Decision Making Co-ordinator know.

This agreement does not cover decisions about finance or assets.

This agreement will not operate after 31 October 2012.

..... name date
..... supporter date
..... supporter date
..... monitor date
..... Cher Nicholson Supported Decision Making Project Co-ordinator date

The Supported Decision Making Project Co-ordinator is Cher Nicholson. She can be contacted by telephone on (08) 8342 8200 or by e-mail: nicholson.cher@agd.sa.gov.au

SDM AGREEMENT UNDER GUARDIANSHIP ORDER

Date

I choose

.....
 .
name, relationship

.....
 .
name, relationship

to be my **supporter(s)** and assist me to make decisions.

I trust them to help me make decisions about:

☐ where I live

☐ who I spend time with

☐ what I do (work / study/ activities)

☐ my health

.....

☐

.

☐

.

I want my **supporter(s)** to assist me by *(for example)*

☐ Providing information in a way I can understand.

☐ Discussing the good things and the bad things that could happen.

☐ Expressing my wishes to other people

☐

.....

.

☐

.....

.

☐

.....

.

I accept to be a **monitor** who will keep track of how things are going with my supported decision making.

Guardianship Order Details: Date Review date

.....

Terms : ☐ Full or ☐ Limited: to ☐ accommodation ☐ health ☐ lifestyle

I

agree to be a supporter and assist make his/her own decisions when he/she asks me to.

I agree to monitor supported decision making by and let the Supported Decision Making Project Co-ordinator know how things are going.

We will review this agreement by
month and year

Any person in this agreement can stop being involved in the agreement by letting the Supported Decision Making Co-ordinator know.

This agreement can be used to make decisions not covered by the Guardianship Order. It can also be used to reach a decision which is covered by the Guardianship Order, however the guardian has final responsibility for decision making in those areas. The guardian will take into account an SDM decision in making their decision. This agreement has full effect after the Guardianship Order is revoked.

SDM agreements will not operate after 31 October 2012.

This agreement does not cover decisions about finance or assets.

.....
<i>name</i>	<i>date</i>
.....
<i>supporter</i>	<i>date</i>
.....
<i>supporter</i>	<i>date</i>
.....
<i>monitor</i>	<i>date</i>

.....

Cher Nicholson

.....

date

Supported Decision Making Project Co-ordinator

The Supported Decision Making Project Co-ordinator is Cher Nicholson. She can be contacted by telephone on ((08)8342 8200) or by e-mail on *nicholson.cher@agd.sa.gov.au*

Appendix E Telephone Feedback Survey Supported People and Supporters

Questions used in the telephone interview seeking feedback from project participants:

- Q01 Was the interviewer easy to get along with?
- Q02 Did you feel the person took time to know some things about you and how you live your life and how you might like to change things in your life?
- Q03 Was there time to talk about what is working well for you as well as what you might like to change?
- Q04 Was the project and you taking part in it explained in a way that was easy to know what was involved?
- Q05 Was the written information helpful?
- Q06 Did you read it afterwards?
- Q07 Were the Pictograms helpful?
- Q08 Were there things you would have liked to spend more time on?
- Q09 Did you feel you were understood and listened to?
- Q10 Was the information given easy to understand?
- Q11 Were you treated well- with respect and dignity?
- Q12 Did you get your questions answered?
- Q13 Were the instructions clear?
- Q14 Were the roles clearly explained?
- Q15 Did you feel you could follow up any concerns (things) afterwards?
- Q16 Were you happy with the outcome result of your interview?
- Q17 Were you given the opportunity to talk by yourself to the interviewer?
- Q18 Were any parts of the talk uncomfortable?
- Q19 Would you like to follow up anything with another person?

Any other comments

Feedback sheet for project participants.

Twelve supporters participated in this feedback.

- Q01 Was the interviewer easy to get along with?
- Q02 Did you know anything about Supported Decision Making before becoming a supporter?
- Q02 Did you feel the person took time to know some things about the person you are supporting and how they live their life and how they might like to change those things?
- Q03 Was there time to talk about what is working well for the person whom you are supporting as well as what they might like to change?
- Q04 Was the project and your participation in it explained in a way that was easy to know what was involved?
- Q05 Was the written information helpful?
- Q06 Were there things you would have liked to spend more time on?
- Q07 Did you feel you were understood and listened to?
- Q08 Was the information given easy to understand?
- Q09 Were you treated well- with respect and dignity?
- Q10 Did you get your questions answered?
- Q11 Were the instructions clear?
- Q12 Were the roles clearly explained?
- Q13 Did you feel you could follow up any concerns (things) afterwards?
- Q14 Were you happy with the outcome result of your interview?
- Q15 Were you given the opportunity to talk by yourself to the interviewer?
- Q16 Were any parts of the talk uncomfortable?
- Q17 Would you like to follow up anything with another person?

Any other comments

Appendix F Police Checks for Supporters - Discussion Paper

Context :

The response from the Human Research Ethics Committee to our application was that we consider requiring police checks for all supporters, including family members. (Our application said we would require police checks for non-family members)

1. The question

Should OPA / the project be 'vetting' supporters identified by participants in the project, at all, and in particular, by requiring a police check?

If yes, to the police check , the following issues arise

- does this apply to all supporters (application says only non-family)?
- what kind of police record would indicate unsuitability to be a supporter?
- what do we do with the information?

2. Issues

The suggestion of requiring police checks (at this stage for non-family members) raises a number of issues:

- vetting supporters undermines the choice of the participant, and
 - indicates a lack of belief in the person's ability to choose a supporter
 - does not conform to the principal choice factor being a trusting relationship between supported and supporter?
 - may offend participants
- what information from a police check would indicate unsuitability?
 - assault?
 - fraud?
 - child abuse/ child sexual abuse?
 - domestic violence?
 - sexual assault?
- who sees the information?
 - who gets to know about the information?
 - Who decides the person is unsuitable
- If a person is considered unsuitable, do we inform someone we consider they are unsuitable and give them the opportunity to respond (natural justice)?
 - do we inform the supported person we consider the supporter unsuitable - and on what grounds (to disclose contents of police check would breach confidentiality).
- If we decide to implement police checks it could be done as a requirement for all volunteers at OPA as it is for all staff?
 - Are supporters volunteers of OPA?
- who will pay for the application?

- Should we be explicit about this in our public information?

Sources to contact which may have canvassed similar issues:

Disability SA - re volunteers

Volunteers SA - policies?

NIDAS - or other established SDM practices - do they vet and how?

Circles of support / circles of friends groups?

Obtaining and using information from National Criminal History Checks

The SDM Ethics approval application stated we will require police checks / criminal history checks for all supporters who are not family members. As we are committed to doing this for at least the first phase of the project we need a process for obtaining and making decisions about the content of these checks. Whilst in the preliminary phase we can collect feedback about participants views about the relevance of a police check.

Letting people know

Our information to potential participants should inform them:

- that a national criminal history check will be required for all supporters who are not family members,
- that the project will pay for the application
- how the information will be used
- how to obtain a criminal history check

Obtaining a Police Check/ Criminal history Check

The person makes the application themselves, and receives the response themselves. We can provide information and forms. We will need a mechanism for payment.

What will we do with the information - a proposal

Proposal:

Who decides

The practice review group or a subgroup of it that group is the relevant group to decide on whether anything in a criminal record indicates that it is not appropriate to include this person as a supporter in the project.

Guidelines

That group would develop guidelines similar to those used by other agencies eg: a person is not suitable if they have a conviction for murder or sexual assault or served a prison sentence for any form of assault. We may wish to include fraud or misrepresentation of some forms. Are there are other offences we should consider? The guidelines could come to the reference group for endorsement.

Record keeping

The record belongs to the person not to the project or OPA. The project would maintain a confidential record of the information which rendered a person unsuitable and any reasoning associated with the decision that they could not participate 9 including the person's own views if any.

Procedural Fairness

We must provide a person with the opportunity to confirm the accuracy of the record and provide any other relevant information to the conviction.

If they are considered unsuitable they may wish to voluntarily withdraw from the program without a reason being cited to any other parties.

Telling the supported person?

There are few models to guide us here. Does the supported person have any right to know what is on their trusted friend's criminal history check? I don't think so. If the potential supporter withdraws voluntarily and we consider them a potential risk to the supported person - do we have obligations to take steps to protect the person?