



Developing a Model of Practice for Supported Decision Making

Background information to assist the facilitation of agreements.

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This is an iterative document.

Information about updates of this publication will be posted on www.opa.sa.gov.au when available.

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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 Introduction

This document provides a framework for practitioners who wish to assist their client set up a Supported Decision Making arrangement.

It has been prepared for the South Australian Supported Decision Making trial, and provides the initial practice guidelines for the intervention that will be formally evaluated.

The document is iterative – it is expected that as more understanding is gained through the trial, this resource will be regularly updated. The supported decision making intervention therefore is not a fixed one – as it will be adapted to the needs of individual clients, and evolve using a continuous improvement approach. This will be based on the experiences of clients and practitioners in conducting the trial.

Another purpose of this document is to cross check the Supported Decision Making practices with the UN Convention on the Rights of Disabled Persons, the key driver of this trial.

In addition in providing this service participants will have the same rights that any person in the population will have when receiving a professional service from a government agency, and the rights of participants in a research program consistent with the approval of this trial from the SA Health Ethics Committee.

1.1 Aims of the Supported Decision Making Trial :

- 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 with those agreements.

2 Background

2.1 United Nations Convention on the Rights of Persons with Disabilities

The purpose of the UN Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

As a person makes individual decisions, rights associated with all parts of the convention may be enlivened. The convention can be accessed at the UN Enable website (UN Enable, 2006).

The Supported Decision Making Trial has been designed in response to Article 12, *Equal recognition before the law*.

The Trial must also apply the Guiding Principles of the Convention and other articles of the convention.

A principle aim of the trial is to administer Supported Decision Making within an appropriate safeguarding framework. This will be guided by Article 16, *Freedom from exploitation, violence and abuse*.

Supporting decision making is a form of reasonable accommodation, and therefore Article 5 *Equality and non-discrimination*.

2.1.1 Equal Recognition before the law

Article 12 is the key driver behind supported decision making, as state parties shall take appropriate measures to provide support to people so that they may exercise their legal capacity.

The United Nations explains Article 12 and the use of supported decision making in the following way (United Nations Secretariat for the Convention on the Rights of Persons with Disabilities, 2008):

The Convention recognizes that some persons with disabilities require assistance to exercise this capacity, so States must do what they can to support those individuals and introduce safeguards against abuse of that support. Support could take the form of one trusted person or a network of people; it might be necessary occasionally or all the time.

With supported decision-making, the presumption is always in favour of the person with a disability who will be affected by the decision. The individual is the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual. Even when an individual with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual.

Article 12

Equal recognition before the law

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

2.1.2 Freedom from exploitation, violence and abuse

The United Nations Secretariat in summarising Article 12 notes that there should be safeguards introduced against the abuse of that support.

The population of people who have cognitive impairments are at a higher risk than the general population of becoming the victim of violence. This is often perpetrated by a person known to them such as intimate partners, family members, friends, or care providers.

A recent Victorian Office of the Public Advocate survey described 86 cases of violence, abuse and neglect perpetrated against advocacy/guardianship clients of that office. The authors noted a need to improve coordination between services and develop shared understandings of violence and disability (Dillon J, 2010).

In Australia our approach to safeguarding is limited compared to universal adult protection strategies in place in the United Kingdom (This has been previously discussed by the SA Office of the Public Advocate in its 2009 and 2010 Annual Reports, and is the focus of another research program currently underway from the office.) This can lead to a reliance on guardianship to keep a person

safe, when other practical strategies should be used that might keep an at risk person safe in the community without taking over their personal decision making.

Article 16 *Freedom from exploitation, violence and abuse*, can be the foundation of a safeguarding framework.

This article suggests the provision of information and education about abuse, along with assistance in recognising and reporting it.

This can be conceived as a right to safety – as opposed to historical approaches to people with disability that have involved taking away their rights to keep them safe, which in itself has frequently been an ineffective protection.

For a supported person, having decided that they wish to participate in supported decision making, the next decision – who will be my supporter – is perhaps the most critical.

Supported Decision Making practice needs to allow a person to choose their supporter, but to do this as part of a process that maintains a right to safety.

The Support arrangements will also include a third person, a monitor, who can assist with problems but also take on a safeguard monitoring role.

The Office of the Public Advocate will also be monitoring this program closely, as a new program that is being evaluated. This will provide another avenue to report concerns. In the future if supported decision making is legislated, and the participants have legal obligations it may not be necessary to provide this extra oversight and easy access to help.

Article 16

Freedom from exploitation, violence and abuse

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.
2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.
3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.
4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.
5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

2.1.3 Equality and non-discrimination

Article 5 *Equality and non-discrimination* also has particular relevance to this trial. While decision making research illustrates that many people in the general community have difficulty making decisions, this is often unrecognised and it is people with disabilities are often called on to demonstrate their ability to make key decisions when members of the general population are not

Article 5 also requires that reasonable steps be taken to ensure reasonable accommodation is provided. This applies to decision making. So while a person may benefit from a supporter, this does not absolve services or other community agencies from taking necessary steps to communicate with the supported person. This may include adapting the way information is presented to their clients, and allowing more time to communicate important information.

For this reason in setting up a supported decision making agreement, necessary reasonable accommodations that an outside organisations may need to take should also be considered. As with any citizen, a person should hear information directly from a service provider. It may then be discussed with a supporter.

Article 5

Equality and non-discrimination

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.
2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.
3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.
4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

2.2 Supported Decision Making

Exactly what is supported decision making, and why is it necessary to set up agreements? At its broadest supported decision making is a natural part of life. Nearly all people faced with a significant decision will seek the support of others and such relationships are not usually defined in agreements.

This trial will assist people set up arrangements when they have not developed naturally by themselves or participants want help to make them work better.

2.2.1 Stepped Model of Supported and Substitute Decision Making Model

Figure 1 is a Stepped Model of Supported and Substitute Decision Making completed for this trial. As can be seen from this diagram there is not just one form of supported decision making within the total spectrum. Different forms of supported decision making agreements may suit different people.

With respect to Supported Decision Making the two key differences in the types of agreements are (1) the presence or absence of recognition in legislation and (2) who makes the appointment – the person themselves or a tribunal.

In the South Australian trial there is no legislative recognition, and the supported person makes the appointment of the supporter.

It is relevant to explain the stepped model further to see where supported decision making fits into the spectrum.

Not all definitions are agreed in the literature (for example some authors use the terms Assisted and Supported Decision Making interchangeably) but this stepped model can be used as a useful schema.

Autonomous Decision Making: At the top of the stepped model is autonomous decision making. However, autonomous decision making does not necessarily mean individual decision making. Most people will choose to seek advice and support from others when making an important decision. For this reason decision making can be seen as “interdependent” as opposed to independent.

Assisted Decision Making. While definitions vary, in assisted decision making a person is regarded as having legal capacity, but requires assistance to collect information to make a decision. This can be communication assistance – for example a person who has had a stroke may need to communicate with a special device. For people who have an intellectual disability Assisted Decision Making may require information to be presented clearly in plain English with the use of diagrams if needed.

Assistance can be provided by anyone including service providers. Providing necessary assistance is a “reasonable accommodation” and is supported by Article 15 of the UN Convention. While a “supported decision maker” may offer assistance too, the presence of a supporter should not stop a service provider from providing assistance.

A non-statutory Supported Decision Making agreement: The appointment of a supporter is made by the person needing support. The person must want to have support making decisions, and have a trusting relationship with someone who will be their supporter. The person also must be able to

cancel an agreement at any time if they are unhappy with its operation. Agreements can also specify a third person – a “*monitor*” – who can check to ensure that the agreement is operating as it should.

Without a specific law, an agreement acts as a record of the person’s wish to receive support from another. It will not give the supporter any additional standing, and a supported person will not be obliged to use the agreement.

This is the type of agreement used in the South Australian Supported Decision Making trial.

A statutory Supported Decision Making agreement : This has most of the same features as a non-statutory agreement, but in jurisdictions that have Supported Decision Making laws, this legal recognition has advantages in safeguarding the supported person, and giving a special status to supporters.

A legislated form of agreement can create obligations on the supporter to act in the interests of the supported person, and also give their role legal recognition so that health services and community agencies can share information directly with supporters.

Legislation can also include protections from liability for supporters and other parties assisting a person to make decisions provided that such actions are not in breach of the supporter’s duty to the supported person.

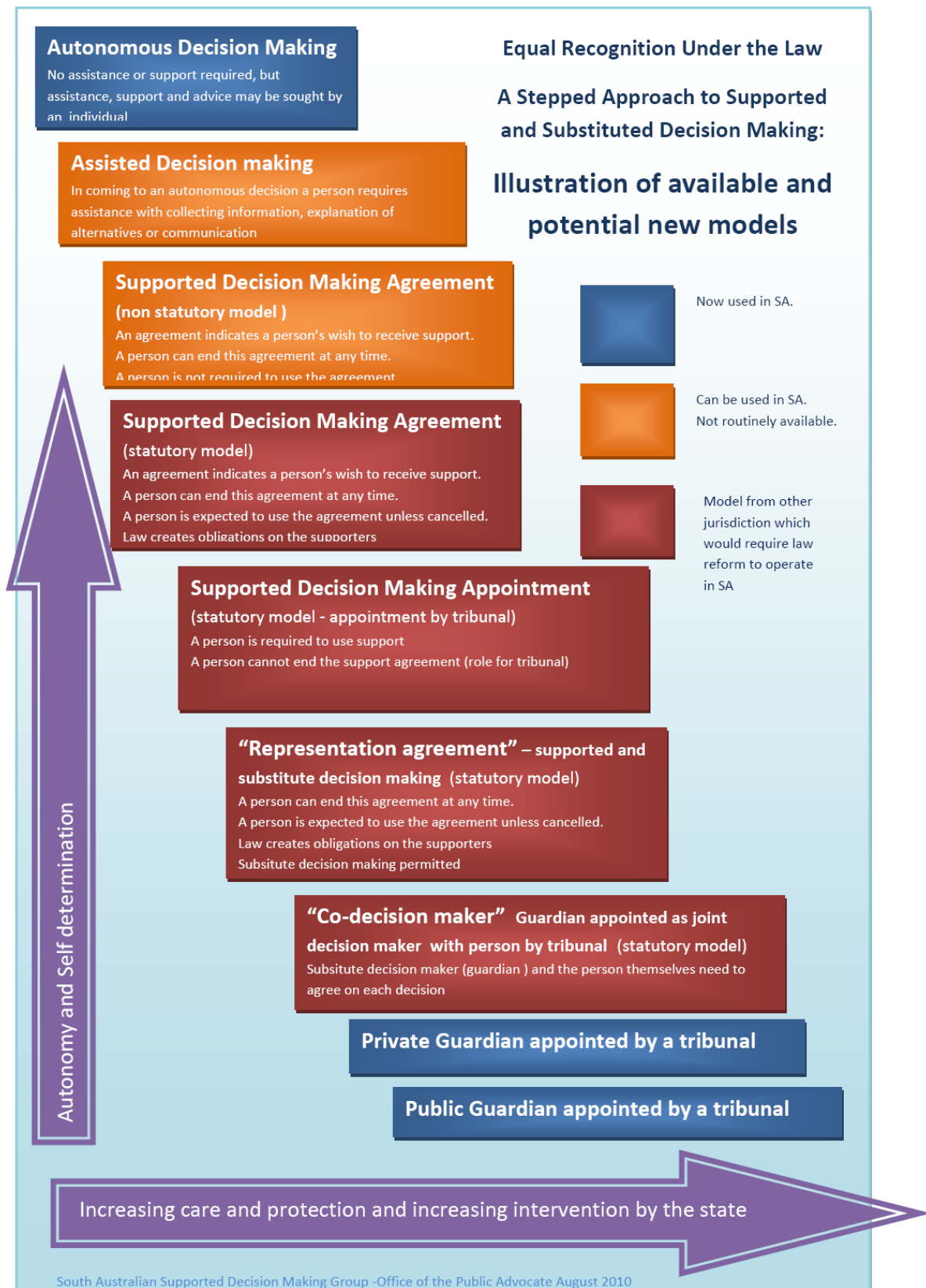
A supported person is expected to use the agreement – if the person wishes to make decisions outside it then a person should cancel the agreement which the person has the power to do. The agreement is a significant document that cannot be ignored.

In conducting the South Australian trial, we consider it likely in the future that any widespread use of Supported Decision Making will require statutory recognition.

A tribunal appointed Supported Decision Making arrangement: Unlike the agreements already described, a person would not have the option of ending an agreement unilaterally as only the tribunal has the power to do this, and would be required to seek support in making decisions while the agreement is in place.

Representational Agreement:. Such agreements are intended primarily to provide Supported Decision Making, and a person appoints their supporters through signing an agreement document as described previously. However, representational agreements also permit the supporter to make a substitute decision if the supported person is unable to make a decision themselves – for example, if the person became unwell and is in hospital. This model, as practiced in British Columbia allows for both supported and substitute decision making.

A tribunal appointed Co-decision maker This is an arrangement used in Alberta. If an adult needs support with decisions a co-decision maker can be appointed by a court. The co-decision maker, who is usually a family member or close friend, and the adult, need to agree on major decisions. If there is a disagreement the decision of the adult (not the co-decision maker) takes precedence. If the arrangement is not working it may be followed up by the Public Guardian to determine if another person should be appointed co-decision maker or another form of decision making support is required.



2.2.2 A non-statutory model of Supported Decision Making

In a non-statutory model, there are no immediate benefits of recognition of the agreement. In comparison in a statutory model, the agreement is defined in law and has value in itself, as it will be recognised in the community.

For the purpose of this trial we expect if the non-statutory agreement is to benefit an individual, the actual support must be useful, as the agreement itself will not have any other benefit other than setting up the support arrangement. The benefit will derive from what is behind the agreement rather than the piece of paper itself.

Key tasks for the practitioner in serving the participants (the supported person, the supporter and the monitor) are to provide professional advice, education and resources. This is input that the participants should find useful, that will assist them decide whether or not to proceed with a supported decision making agreement, and if they do proceed, help make the supported decision making arrangement a success.

2.2.3 Supported vs Substitute Decision Making

While potential misuse of an agreement may take many forms, a particular concern is that a supporter may not respect the wishes of the person that they are supporting, and may take over decision making and act as substitutes without authority.

The SA trial is addressing this by seeking to ensure that all parties understand the support nature of the relationship, have confidence that decisions can be made with support, and are willing to work within the limits of the role.

If a potential support person harbours doubts about the ability of the supported person to make the final decision, has difficulty separating their own view about what should happen from the views of the supported person, or seeks to influence the person then that person would not be able to function effectively to take on the role.

In providing information and education about supported decision making to participants it is hoped that both potential supporters and supported people will be able make their own conclusions about whether or not a potential supporter can function in the support role.

“Substitute decision making” can apply to the decisions themselves, but also to the way people make decisions. Decision making research makes it clear that people can not only differ in their preferences for different options, but also how a person goes about making a decision and applying judgement. Dowie (2002) has described this difference in the way a person goes about making a decision as a *meta-preference*.

These differences also need to be recognised and respected, so that the supporter does not inadvertently substitute their own decision making style for that of the supported person as there is no evidence that one persons way of going about making a decision is better than anothers.

For example one part of Dowie's model notes that people vary in the amount of evidence they require to make a decision, and their level of analysis as opposed to the use of intuition. A supporter will need some insight into how their way of thinking may vary from the person that they support.

2.2.4 Decision Making in the General Population

Diagram 2 considers components of the decision making process for any person based on concepts commonly in use in the decision making literature. It illustrates the interaction between the decision, the context of a person's life, the information and data available, personal values, personality and decision making style.

The "*decision making context*" is the broader context of a person's life and their community. It might include particular aspects of a person's day to day life (eg recreational and work activity and involvement in community), the strengths and limitations of the service systems that assist and support an individual (for example the availability of health care and accommodation) and societal expectations.

Part of the challenge for supported decision making is that it is very likely that context for many people lives has been unnecessarily constrained. Many people with a disability have had a lifetime of being told what they cannot do. Limitations in support services and housing choices may be accepted as inevitable so a person may not even bother thinking about what they really want.

"*Information and data*" refers to details of the available options, benefits, risks and the impact on life style if the decision is made. This may need to be intensive – for example people who move from institutional accommodation to the community may need to make a significant effort to get enough information about a community option if their only experience is of institutional life.

In addition work in health decision making McCaffery et al (2010) has illustrated the difficulties that people in the general population have in correctly understanding information and making decisions. Problems can be even greater for adults with low literacy. In a recent survey in Australia 46% of the Australian population did not meet a minimum level to meet the "complex demands of everyday life and work in the emerging knowledge based economy (Australian Bureau of Statistics, 2008).

In many instances decision-making could be improved with clearer communication, and information aids that could help many people in the population. People with disabilities receive greater scrutiny of their decision making, which may be limited by many of the same factors that affect a much larger group in the population generally.

Decision Making Process

Decision Making Context

Autonomous Individual

Information and Data

Aspects of Day to day life

Limits of care systems

Societal expectations

Consideration of decision

Culture
Lifestyle
Past experience
Decision Making Style
- Speed
- Care and caution
Temperament
Personality

Values and Utilities

Risks and Benefits

Resulting lifestyle change

Personal Preferences

Interdependent Decision Making
Family, Friends and Service Providers

Legal Capacity Considerations
Ability to:
Understand the facts involved
Understand the main choices
Weigh up the consequences of the choices
Understand how the consequences affect them

Decision

"Disability Movement" Capacity Considerations:
Ability to express a preference
Evidence of a trusting relationship

2.2.5 Impulsivity and Supported Decision Making

People differ greatly in their behaviours and the decisions that they make. This has been a significant focus of psychological research examining how decisions are made in all walks of life.

In this broad and complex area there are many theories and approaches that could be examined. Two particular areas relevant to this project are the relationships between personality and risk assessment, and personality and impulsivity.

In practice while Supported Decision Making may serve a range of functions, for some people, for example those who have experienced a brain injury leading to disinhibition and impulsivity, one function of the support process will be to slow down decision making and give time for consideration and reflection about different options.

However it should not be assumed that so called “normal” decision making is rational. In the past decision making was considered to be based on rational choice, but more often, human decision making is based on reward motives rather than long term risk assessment. Franken and Muris (2005) note that researchers in the area generally agree on two fundamental motives for decision making – the desire to reduce pain or uncertainty and the desire to obtain pleasure.

To assess decision making psychological researchers have attempted to replicate real life decisions with a standard psychometric test. Bechara and her colleagues (1994) in Iowa City designed a novel task to replicate real life decision making that incorporates potential uncertainty in outcomes and premises as well as reward and punishment. The test is now known as the Iowa Gambling Test involves subjects selecting cards from different decks that either earn money (subjects are given play money) or may require a penalty to be paid. To score well on the test a subject must stop themselves from responding to an immediately rewarding stimuli to maintain a longer term strategy and the test is considered a measure of “emotionally controlled decision making” (Maurex et al, 2009).

The test has been used in informative studies of experimental subjects (such as psychology students) and patients who have a neurological or psychiatric diagnosis.

For example Franken and Muris (2005) based on their study of psychology students concluded that behavioural decision making (as measured with the standardised task) is not only effected by neurological and psychiatric disorders, but to some extent by higher order personality traits and decision making style.

Once again there is a need to recognise variation in personality and decision making style between individuals, however to note that sensitivity to reward, speed of decision making, and assessment of risk may be influenced by some disorders.

3 The Supported Decision Making Agreement

3.1 Types of Decisions Covered

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

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 choosing specific providers.

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 Distinguishing Supported Decision Making from other interventions

There is a risk that supported decision making can expand beyond its scope. Because all human behaviour reflects decisions whether to act or not act, there is a potential for supported decision making to become all encompassing. Instead as can be seen from the scope of decisions included above for this trial it has a specific practical focus. A person would make the same decisions that might otherwise be made for them by a guardian.

3.2.1 Decisions relate to a specific course of action

These decisions are generally practical and specific. For example: *I will move to a new home; I will spend time with this person but not with someone else; I will accept support services from this care provider if they meet certain conditions, I will commence a training course in a specific area; I will spend my spare time playing a certain sport; or I will take the medicine offered by the doctor first, and only have an operation if the medicine does not work.*

3.2.2 Supported Decision Making is not counselling or therapy

There are broad problems in life that people in the general population people will either talk through with friends in an informal way, or if the problem is significant, go to a specific professional to deal with (eg a therapist, counsellor, vocational guidance etc). The supported decision making agreement is not intended to replace general support discussions with friends on one hand or visits to professional services on the other, even if these problems are framed as a decision. For example - *I feel unhappy about who I am, I do not like myself, and cannot decide what to do with my life which will give it meaning.*

In this situation a referral to Supported Decision Making program by itself would be insufficient, and if a person knows they want to seek help they may be better referred directly to a counsellor. However if a person does have an agreement, and is experiencing such a problem and is not sure what action to take, the supporter may be used by the person to help decide whether they wish to talk through these issues with friends, or alternatively if the time has come to seek help from a mental health or other professional. The supporter may help the person decide which professional they wish to attend.

Another example would be decisions about substances – *I want to reduce how much I drink; I want to stop smoking*. A supporter may help in the decision making about whether or not to get help, and where to obtain it, but recognising that they are not a substance misuse therapist.

In all these situations it is useful to consider how citizens generally seek out and obtain help making decisions. Depending on the situation there may be a range of community resources that may give information and advice on particular topics and offer services. The supporter is not a replacement for these community functions, but may assist a person decide when to access them, and whether or not to act on the advice received.

A specific instance of professional consultation relevant to this trial is the provision of cognitive rehabilitation for people who have experienced a head injury. A program may be developed by a psychologist that will ultimately assist a person with making decisions as they gain benefit from rehabilitation. A decision supporter can complement this, but they are not a replacement for this professional work. A decision supporter may also need to progressively reduce their own interventions as a person regains skills and can resume a greater role.

3.2.3 Supported Decision Making is not mentorship

The supporter in a Supported Decision Making agreement is not intended to be a mentor. Any citizen may want a mentor, and people benefit from the trusted advice and modelling that a mentor can provide. However the support role in decision making is different. A person may model themselves on a mentor, but this is not the intention of having a supporter. If a person were fortunate enough to have a different mentor and supporter, a supporter may assist a person decide whether to follow a mentor's approach or choose a different course of action. If a supporter already has a mentorship role in a person's life, there would need to be strategies to separate the times that mentorship is delivered as opposed to practical decision support.

3.2.4 Support role and advocacy

Another area of potential overlap is advocacy. Supported Decision Making is distinct from advocacy. If a person is assisted by a supporter to make a decision, part of this process may be communicating the outcome of a decision. In this context it is then inevitable and also desirable that the supporter becomes an advocate.

However if a person wants an agreement because they are not being listened to, but they are well able to make decisions, then advocacy would be the primary intervention to recommend. This could be training in self advocacy, advocacy from family or friends or a formal referral.

Clarity about the scope of supported decision making is relevant both initially, when a person is making a decision about whether and not they need supported decision making, and then during the operation of the agreement.

3.2.5 Exclusions of decisions about illegal behaviour

Another example of out of scope decisions are those that relate to illegal behaviour. *I want to hit my housemate; I keep stealing things and end up back in gaol; I want to try party drugs.* The Supported Decision Making agreement used in this trial has to operate within the law – supporters will not consider options that are illegal.

If a person wants help to stop offending behaviour the supported decision making agreement may be used to decide which help to seek and then accept. If a person has identified that they need to look for work and recreation as an alternative to crime, then a supported decision making agreement could assist in this area.

It is highly likely that an effective Supported Decision Making arrangement may assist a person avoid breaking the law – for example in areas of impulsive behaviour.

However it also has to be acknowledged that most of the thinking about Supported Decision Making internationally has been considered as alternatives to either guardianship or civil commitment under the Mental Health Act. How supported decision making may or may not relate to the provisions for criminal responsibility in legislation that allows for mental impairment defences have not been analysed, and therefore needs exclusion from any trial.

3.2.6 Exclusion of decisions about marriage, voting and religion

The Supported Decision Making agreement would not be used to make decisions about marriage or who to vote for at an election, areas traditionally excluded from decision making by guardians. Because a supported person and supporter will likely have a personal relationship that will be broader than the supported decision making agreement, these topics may very well be discussed, in the same way that people talk about life decisions.

However the Supported Decision Making approach would not be applied to these areas. (Therefore the outcomes of supported decision making agreements will not be presented to marriage celebrants, electoral officials, or religious leaders!)

3.2.7 Supporters will have other roles in a supported persons life

With respect to the latter point, supporters who mostly will be friends and family, will have many different roles in a person's life well beyond the scope of supported decision making. However at the times that a supported person and supporter sit down to discuss a decision it should be clear that at those times it is the supported decision making role the person is taking on.

As part of preparing participants for their roles, it may be for some participants planning and rehearsal will be needed. It may be necessary to set time aside for discussions about decisions. These conversations may be different to the usual day to day conversations and other interactions

the supporter and supported person may have. These conversations would consider specific decisions, while it is recognised that there will be broader and wider interactions at other times.

The issue of whether or not this is excessively formal is discussed later in the document. It can be argued that in everyday life support is not usually delivered this way. Using this argument, there would be no need to provide education about “support”. People could go away having signed an agreement and decide for themselves what support is.

While this may work on many occasions, there are others where it may not. For whatever reason people who are signing these agreements have not had support delivered naturally.

In this trial, the agreement is not an end to itself (which is partly because the agreement is not formally recognised in law). The benefit to an individual comes not from the agreement but from the ongoing support relationship established by the agreement.

3.3 The Roles of the Parties to a Supported Decision Making Agreement

The requirements and roles of each of the parties have been summarised below.

This information can be discussed with people who may wish to have support, to consider if supported decision making will assist them. It can be used with supported people, and potential supporters and monitors to consider whether a potential supporter or monitor can take on this role, and fulfil the tasks.

The selection of a supporter requires not only that a supported person wants that person to take on the role, but also the potential supporter themselves must be confident that they can do it. This includes having a level of personal insight to manage potential conflict of interest. Faced with a decision that the supporter may have a strong personal view about, can the supporter deliver impartial support in these situations?

3.3.1 The Supported Person:

A supported person will need to be able to:

- To express a wish to receive support.
- To form a trusting relationship with another person (s)(supporter or monitor).
- To indicate what decisions they may need support for.
- To indicate who they wish to receive support from for which decision.
- To express a wish to end support if that time comes.
- To be aware that they are making the final decision and not their supporter.

3.3.2 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.
- To form a trusting relationship with the supported person¹.
- 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.

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 (eg available options, potential outcomes)
- 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 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 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.

3.3.3 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.

¹ The requirement for the supporter to form a trusting relationship with the supported person was added prior to the commencement of phase II. This requirement matches the statement for the supported person.

3.4 Suitability for supported decision making agreements

There are two questions for suitability.

3.4.1 Suitability for Supported Decision Making

The first is the suitability for a supported decision making agreement itself. The decision about suitability is determined by self selection. The parties to the agreement decide for themselves if supported decision making will assist them and if they can take on the roles as described in the previous section.

Supported people, supporters and monitors each have to make a decision if the role can be fulfilled.

A facilitators role is to help people make this self selection.

3.4.2 Suitability for the SA Trial of Supported Decision Making for adults with disability

The second question of suitability is for the trial. People who are participating in the trial are a sub-group of the larger group who may benefit from Supported Decision Making. This is because in designing the trial, the Supported Decision Making Group decided on key exclusions in phase I.

Exclusions are :

- People who experience abuse or neglect, or are at the centre of significant conflict amongst family and friends.
- People who have a degenerative dementia. Practices overseas vary in this regard. A person with a deteriorating course may lose their understanding of the process and no longer be in a position to cancel an agreement if they chose to do so. For this reason it was decided not to include this group in this trial, although there is evidence that supported decision making approach can benefit people who have a dementia.
- People who have mental illness as a primary disability. This trial aims to study Supported Decision Making in the context of guardianship, not Mental Health Legislation. The latter would require further specific strategies.

The first reason for exclusion - abuse, neglect or significant conflict - will be reconsidered in phase II. This matter has been discussed in the project control group.

In the case of abuse, the only absolute exclusion would be if an alleged perpetrator wished to be the supporter, and had not been cleared of allegations. If a person is now safe, having experienced abuse is not a reason in itself to be excluded.

In providing “a right to safety” under Article 16, a range of mainstream mechanisms may need to be invoked at the same time – including practical social work assistance to ensure safety, and assisting a person refer matters to the police.

As part of phase I a police check for non-family supporters was included as part of the research protocol. This generated a mixed reaction from supporters themselves, and was discussed

extensively in the project committee. This requirement will be modified in phase II. A discussion in the matter is included later in this document.

Similarly, while family conflict may make supported decision making difficult it does not need to be an absolute exclusion. For example if the supported person chooses one member of the family who is in conflict with another member to be a supporter it may make the task of supported decision making more difficult.

However in phase I there has already been experience where a person has chosen a family member as a supporter (who is in significant conflict with another family member). At this time the choice has not been challenged. In another matter a person with significant conflict in their family voluntarily sought an agreement having already successfully argued for a guardianship order to be revoked.

The other exclusions regarding mental illness and people with a deteriorating capacity are likely to remain in phase II.

Supported Decision Making arrangements for people who have a mental illness often need to respond to the needs of people who have a fluctuating requirement for support. The new *Mental Health Act 2009* legislates for people to have access to support when unwell (Section 47). Arrangements can also involve signing advance directives (Ulysses agreements) when well which are then activated when a person experiences a relapse. These agreements will be incorporated into new advance care directives legislation.

The current trial is focussed on supported decision making as an alternative to guardianship orders, rather than Mental Health Act orders.

With respect to the inclusion of older people who have dementia, practices overseas vary in this regard. There are possibly ways to involve older people in supported decision making. Aged rights advocates see it having a role in early to moderate dementia. If a person has an advance directive as well as supported decision making, an advance directive can be activated when they are no longer able to make their own decisions with support. Further use in aged care will require extra work.

It is also relevant to note the exclusion of financial decisions from the trial. This is principally because the trial originated in a guardianship office, rather than a trustee office. A definitive model should include financial management. We consider that this would need legislative endorsement if the process were extended to significant decisions, although a non-statutory model could still potentially be used for day to day financial matters.

3.4.3 Two streams to the trial

The particular groups to be recruited are-

- An early intervention stream. In this group guardianship will not yet have been considered. It will include young adults with an intellectual disability, and people of any age who have recently experienced an acquired brain injury or been diagnosed with a neurological disease.

- An alternative to guardianship stream. This will be offered to people who are subject to an inquiry or application for guardianship, and would have otherwise received a guardianship service from this office if it were not for the trial. It will include people under guardianship who may no longer be suitable and then have guardianship ceased.

3.5 Reasons for Opting for a Supported Decision Making Agreement

Reasons will depend on the individual. The reasons for choosing supported decision making may influence the information and education required for a person in each situation.

In this context the reasons for Supported Decision Making may include

3.5.1 To End Informal Arrangements that involve substitute decision making

For most people the agreement will replace what in the South Australian Guardianship and Administration Act 1993 is called an *informal arrangement*.

It is often assumed that “informal arrangements” are in some way synonymous with supported decision making, whereas in fact, informal arrangements frequently involve informal substitute decision making.

By agreeing to a supported decision making arrangement, the parties are also agreeing to end informal substitute decision making.

The supported person may wish this, so that they can gain more independence, but retain important personal supports and relationships.

Family and friends may also want this for their family member. (In Canada it was the family members of adults who had intellectual disabilities who pushed for legislation to allow supported decision making.)

In phase I there have been examples where the supported person nominates the previous informal decision maker to become the supporter (for example the parent of an adult child). In some other situations supported people have chosen someone different, or opted for two supporters to work together – the previous informal decision maker in the home, and someone else outside the home.

Participants may need to be made aware that in some instances supporters will be surrendering power that they may formerly have had as informal substitute decisions makers. Most will want to do this. For example it can mark a positive transition into adulthood after turning 18.

3.5.2 For a person to take back control of their life

This is similar to the previous reason, but is more general, and refers to the loss of control people with disabilities can experience because of their dependence – on both provider organisations and other people in their lives.

The agreement acts as an affirmation that the person with disability is in control of their life. In Phase One of the trial, some participants have been delighted when they signed their agreement. It was a cause of celebration. For some people it was one of the rare occasions in their life that

someone has expressed confidence in their ability to make decisions. The agreement gives choice and power to make a decision rather than doing what others say.

Discussions in our project control group put this in the broad perspective of the lived experience of people with disabilities. People living with disabilities can learn from experience at an early age that they cannot make decisions. They learn not to speak up, learn that others will make decisions for them, and then become passive, not because of limitations from a disability, but learned limitations from these formative experiences.

This is reinforced through dealing with professionals and with disability services: repeated assessments to be told what you cannot do rather than what you can, and under resourced support and therapy programs that offer little choice.

Pressures can also be applied to family and carers who can be under pressure to conform. If services and families are in conflict the prospect of having a guardian appointed can be raised.

These are real experiences for many people living with disabilities and can this can be irrespective of the nature of a person's disability. These comments are not intended to reflect on the hard work of disability workers providing services in adverse circumstances. Recent changes such as individualised and self managed funding also return control to individuals.

3.5.3 To Provide for Decision Support to Be Available

This would be the expected and obvious reason to seek an agreement.

This can apply to people who are isolated and do not readily have another person in their life with whom to readily discuss decisions with. The Supported Decision Making agreement can provide a structure to establish a new kind of trusting relationship with a person that they may already know in another context, or have come to know through circles of friends and other programs.

It can also apply to people who already have others in their lives, but for various reasons have not been able to sit down with these people, to spend time talking about decisions, and their need for decision support has not been recognised.

The agreement in these situations is a mechanism to ensure that a need for decision support is identified, and people set time aside in their schedules for it to occur.

3.5.4 To Provide for an Improved Quality of Decision Support

Support may be naturally available to a person and discussions about decisions may already be happening. However participants may also recognise the need to improve how this support is delivered.

For example existing discussions about decisions may be characterised by the giving of advice rather than support, or may be discussions based on assumptions that the supported person will do what others suggest, or choose from options already narrowed down for them.

Developing a supported decision making agreement, provides education about decision making, recognition of how each individual makes decisions and how support can be best provided for that person.

3.5.5 As an alternative to guardianship

This applies to both the “early intervention” and the “alternative to guardianship” streams. For people in the early intervention group it is conceivable that an effective supported decision making arrangement may prevent the need for guardianship many years hence. It will not be possible to prove this with our 2 year program.

The need to prevent guardianship is axiomatic. Key international documents aim to limit that role. For example the UN Convention Article 12 requires that guardianship be proportional and tailored and apply for the shortest possible time (UN Enable, 2006). The Yokohama Declaration on Guardianship indicate that a person should only be considered unable to make a decision after all practical steps to help him or her do so have been taken without success (International Guardianship Network, 2010). The Australian Guardianship and Administration Council, the peak body for public guardians, public administrators and tribunals in Australia, has endorsed the latter document.

Already in phase I one person has successfully argued to the Board to have her Guardianship Order revoked, declaring her interest in Supported Decision Making. Another application for Guardianship was refused, because by the time the matter was heard the person who was the subject of the application had decided to pursue a Supported Decision Making agreement.

In two other cases people supported decision making has been raised with the Guardianship Board, who have made orders, but with the expectation that supported decision making arrangements will be put in place, and orders may in the future be revoked. This has raised the need to trial supported decision making while a guardianship order is still in place. While this may seem contradictory, as a guardian will still make the final decision, a persons “expressed wish” will have greater influence when it has been presented as a personal decision. At any rate running supported decision making alongside Guardianship is only intended as a temporary measure.

3.5.6 Incapacity due to impaired communication

In South Australia an inability to communicate a persons wishes and decisions can meet the criteria for communication.

In phase I at least one person who had a neurological disease joined the supported decision making trial. While it may be argued whether this constituted “assisted” rather than “supported” decision making, the person reported a similar gain in confidence and control in their life.

4 The Practice of Supported Decision Making: Safety and Governance

4.1 The Office of the Public Advocate as a base for the trial

In South Australia our Act has created an office of the Public Advocate rather than Public Guardian. Guardianship is undertaken in the context of the broad roles of the office in promoting rights and interests for consumers and carers and is not an end in itself.

Even though the *Guardianship and Administration Act 1993* was written well before the UN Convention and Supported Decision Making the priority at the time was still on avoiding the unnecessary imposition of guardianship.

In 1993 when delivering the Second Reading Speech, Minister Martyn Evans said

The Bill establishes as a major initiative, a statutory position of Public Advocate. The Public Advocate will seek to resolve problems so that, unless appropriate, the legal processes of the Board need not be invoked. When they are invoked, the Public Advocate will provide significant assistance (Hansard, House of Assembly, 9th March 1993 page 2351).

Later in the speech the Minister went on to say,

The Public Advocate will operate on the fundamental principle of promoting agency and community responsibility rather than seeking to develop an extensive service provision role for its staff. (Hansard, House of Assembly, 9th March 1993, page 2352).

Supporting people to make their own decisions is in keeping with the aim of resolving problems without needing to invoke the powers of the Guardianship Board.

Providing decision support is a community activity – it is not one for a government agency. Trusted family and friends are the people who provide support. In the future it is likely that the work of setting up agreements can be done by non-government community agencies, although this initial trial has been based in our statutory office.

With respect to the specific provisions of the Act, the work promoting supported decision making and facilitating supported decision making arrangements is consistent with the provisions of Section 21 of the Act (which is reproduced below).

First, in terms of the general role of the office, Section (21) provides for program review functions along with the identification of unmet need, the promotion of rights and the making of recommendations to reform the Act. In this context the Office has identified that there is an unmet need for decision support services as opposed to available substitute decision making services, and is promoting this right to obtain support which is an expectation of the UN convention. The current trial will inform recommendations for future law reform.

Second, the Act also permits the office to assist who are currently not under an order with advocacy.

Third Section 21 (1) (f) of the *Guardianship and Administration Act 1993*, amongst other roles expects the Public Advocate to give advice “...on appropriate alternatives to taking action under this Act.” Supported Decision Making is an appropriate contemporary alternative.

21—General functions of Public Advocate

- (1) The functions of the Public Advocate are—
 - (a) to keep under review, within both the public and the private sector, all programmes designed to meet the needs of mentally incapacitated persons;
 - (b) to identify any areas of unmet needs, or inappropriately met needs, of mentally incapacitated persons and to recommend to the Minister the development of programmes for meeting those needs or the improvement of existing programmes;
 - (c) to speak for and promote the rights and interests of any class of mentally incapacitated persons or of mentally incapacitated persons generally;
 - (d) to speak for and negotiate on behalf of any mentally incapacitated person in the resolution of any problem faced by that person arising out of his or her mental incapacity;
 - (e) to give support to and promote the interests of carers of mentally incapacitated persons;
 - (f) to give advice on the powers that may be exercised under this Act in relation to mentally incapacitated persons, on the operation of this Act generally and on appropriate alternatives to taking action under this Act;
 - (g) to monitor the administration of this Act and, if he or she thinks fit, make recommendations to the Minister for legislative change;
 - (h) to perform such other functions as are assigned to the Public Advocate by or under this Act or any other Act.

4.2 Definitive Specific Practice Guidelines to Be Developed

Practice guidelines will be an outcome of the Supported Decision Making project. These will underpin the facilitator’s task to help participants make agreements, and to maintain a right to safety.

These guidelines will develop through the further iterations and expansion of this current document.

As a starting point common approaches to providing assessment, advice, education, information and advocacy have underpinned the provision of an initial service.

Multidisciplinary team discussions have further informed the development of practice in this new area.

Because Supported Decision Making agreement facilitation will be undertaken by a number of practitioners in the Office of the Public Advocate, practice will be standardised as much as possible to ensure that people who seek help from this trial receive similar interventions.

4.3 Supported Decision Making Facilitation as a Professional Task

Supporters and monitors are not expected to behave as pseudo-professionals— support is fundamentally a task for the community. Nevertheless the model expects supporters and monitors to undertake their task effectively and to be informed on the differences between supported and substitute decision making. While they are not asked to complete case notes, a decision making diary is requested to help focus them on the role.

While the key roles are non-professional, the facilitation process in this trial however is a professional task. There are a number of reasons for this. This is the first time that such a trial has been conducted in Australia. The facilitation task still needs careful reflection and development so that it can be documented to the point that it might be undertaken by a broader group of people. Also the trial is implementing a non-statutory model. The safeguarding protections we are using in the implementation of this model include the provision of professional assessment and advice, as well as close oversight of the operation of the agreement by this office.

It is possible then that in the future with a legislated regime that people who wished to set up an agreement would have a number of options. This might include establishing the agreement themselves, or working with a non-government agency who may employ staff with different backgrounds to facilitate the agreements, depending on a person's needs.

4.3.1 Duty of care

In providing this service there is a duty of care to the individuals that we meet with.

All citizens when they consult professionals or a government organisation have a right to expect skilled assessment and advice, that is impartial, and that the professional is fundamentally serving their clients' needs and interests.

The duty of care for the facilitator is principally to the supported person, however professional services are also provided to supporters and monitors –for example in assisting those people decide whether or not to take on the task, and preparing them for it.

4.3.1.1 The participants vs the facilitators role in the decision to proceed with an agreement

A fundamental decision for participants is whether or not they wish to proceed with a supported decision making agreement.

As discussed later in this process, a key task of the assessment process is to help people make up their own mind about whether supported decision making is for them.

This can be the supported persons "first" decision, and of course, it is made before the support agreement is in place. Inevitably the facilitator may need to provide support for this critical decisions – helping the person work through what needs to be considered (eg does the person want support, who from, for what decisions etc).

Similarly, the facilitator will assist supporters make their own decision about what can be offered (eg does the supporter consider a trusting relationship exist, is the supporter prepared to commit time to the task, can the supporter provide support without become a substitute).

It is expected in most cases that this will be all that will be needed. The facilitator will be giving information, and people will make their own minds up. So far, in phase I participants have all been able to make their own decisions.

The facilitator's role is not to determine eligibility or to screen. However, there is also a place for the facilitator to provide professional advice directly, if required. It is conceivable that at times a client

may request a supported decision making agreement but the facilitator may see that a need may be met some other way.

For example this may involve referrals for advocacy or to other mediation services.

In situations where a supported person and a supporter wish to proceed with an agreement that the facilitator considers unsafe, the facilitator is under no obligation to facilitate this agreement, if doing so will put the supported person at risk.

This potential “veto” generated much discussion in our project control group as it could be seen as taking away decision making rights from the supported person. However with any professional tasks a provider has discretion not to provide a service if it is considered inappropriate.

In phase I participants themselves have made all decisions about suitability, and there has been no need for the facilitator to decline to provide a service.

In phase I significant issues have arisen. These have concerned the behaviour and actions of nominated supporters. However, when these issues have come up has been evident to all concerned – supported person, suggested supporter, and suggested monitor – that an agreement as proposed should not proceed. In one such situation the supported person then nominated an alternative supporter. There was no need for the facilitator to do anything other than facilitate.

These situations involve the ability of the supporter to take on the role, and are not a reflection on the supported person.

4.3.1.2 Ongoing advice after the agreement has been signed

When agreements are in place the facilitator can assist the supported person make use of their supporter’s input, and can help the supporter in their task. However, the facilitator’s role is not to provide direct support.

Our office will be giving people ongoing assistance as they use their agreements. This may be particularly helpful if people need coaching in their roles when difficulties arise, or unforeseen problems develop, which the initial preparation of participants did not cover.

When an agreement is operating, it is expected that the need for such coaching of participants will diminish over time.

The focus is on the “process” of support rather than the decision per se. Coaching can be with the supported person on using support, and the supporter and monitor in providing their roles.

4.3.1.3 Cancelling an agreement

The agreement is a statement of wishes for the supported person to receive support, and the other parties to provide support or monitoring.

Unlike in Canadian provinces the agreement is not recognised in law.

The supporter and monitor are not providing professional services as such – instead taking on the type of tasks that relatives or friends might, but with education and coaching from the facilitator.

However if the agreement is not working for whatever reason, it will still be important for it to be cancelled.

Other parties could develop a misapprehension if they believe that a support arrangement is in place, when for whatever reason it is not operating.

In signing an agreement a supporter confirms their intention to provide support, but this can be reviewed at any time.

A supported person should not be left in the situation of being let down because a supporter is either unavailable, unwilling, or unable to provide support.

A supporter should not be in a position of being accused of failing to provide support if decisions made by the supported person without support suddenly go wrong.

All parties can inform the facilitator if the agreement needs to end. The monitor has a specific role in this regard. For this trial the facilitator will be making regular contact with participants to check that support arrangements are working.

Our conversation with a Canadian program indicates that a number of people will be expected to change their agreements in the months after commencing an arrangement. This may involve changing areas of support, but also changing supporter.

4.3.2 Multidisciplinary professional approach

The practise of facilitating supported decision-making arrangements does not belong to any one particular profession.

The practice may involve social workers, lawyers, health professionals, disability practitioners, and other professionals who have had experience in areas such as guardianship.

For this reason as supported decision-making facilitation is a new area of practice, the SA trial has convened a multidisciplinary group to oversee the practice. Such a group may not be required in the future when practice has been defined.

4.3.3 Confidentiality

Standard confidentiality provisions will apply to this work.

However the facilitator by virtue of either their professional role or employment may be subject to other requirements when required – such as mandatory reporting under the *Child Protection Act 1993*, or the *Firearms Act 1977*.

The research consent form gives participants permission for the use of confidential information for research purposes.

4.3.4 Case notes

Information collected during the facilitation task is recorded in case notes. This provides a record of the service provided. These case notes can assist the facilitator when providing coaching and support to participants during the life of the agreement.

In addition, for the Supported Decision Making Trial, informed consent is obtained so that casenotes can be used for the purpose of research evaluation, while still retaining confidentiality.

4.4 Does this model unnecessarily formalise a “natural” process of support?

Supporting other people to make decision is a natural task for people. It is a part of human relationships. In the most general sense, there is no right or wrong way to provide support, and training is not needed.

In contrast, this model has broken down decision making into its component parts. There is an expectation that a person will follow key elements of a defined process, by recognising that a decision needs to be made, and seek out their supporter(s). Individual decision making style and preference are acknowledged, but the task of decision making that is usually spontaneous and natural, becomes planned, considered and methodical.

In this respect decision making is no different to any other natural function that may be lost because of a health condition that causes a disability. Whatever the area of disability – it may be speaking, walking or attending to daily living skills such as showering or preparing meals - rehabilitation therapists and care workers break tasks down and sequence them. This information is given to the person themselves, as well as family and carers who help the person on a day by day basis. Through practice and experience skills are acquired, confidence builds and tasks become more “natural”.

Therefore if a person cannot undertake a task because of a disability, then helping the person do this task by breaking it down into its component elements, and seeking help from a supporter is a reasonable strategy.

Like any other skill, decision making should respond to training, and rehabilitation. The process builds on strengths. Such rehabilitation approaches can be described as “capacity building” – a term that takes on added significance when the capacity that develops is decision making “capacity”.

Ideally all people using supported decision making should gain confidence, and need less support. Depending on an individual persons circumstances, this might be a significant improvement so that supported decision making is no longer necessary, or a smaller improvement for a person who has a more profound disability, who may continue to need support, but may regain more personal responsibility and control over the process.

Education about Supported Decision Making can clarify the nature and purpose of a conversation about a particular decision. Outside an agreement, support in its most natural form may be delivered as just one part of a range of communications. A family member or friend may one minute provide support, but in the next attempt to influence, advance their own arguments, or even pressure a person into a course of action. The recipient of this support/advice/influence/argument

needs to work out the motivation of the other; and to determine if they have they been supported, influenced or argued to, and whether or not they should act on what has been heard.

With a supported decision making agreement, the structured arrangement makes it clear to all parties, in particular the person who has a cognitive disability, what should be happening in a particular conversation. When the supported person contacts a supporter to discuss a decision, for the duration of that conversation, what will be provided is support, and nothing else. Supported decision making provides clarity about the purpose of an interaction.

Summary of use of agreements by participants in Phase one and any specifics that they added.

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.

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

Standard inclusions in the agreement were:

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

Some of the additions to this section were: -

- Listening to me first and try and understand (home with family)
- Remind me to look forward and think of the future (living with family)
- Support with specific information re court (sharing house temp)
- Support with responsibilities / advice (sharing house temp)
- Sometimes helping me to communicate (residential)

I trust them to help me make decisions about: -

Standard inclusions in the agreement were:

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

(All participants ticks of agreement to all parts of this section)

Some of the additions to this section were: -

- 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 (Private house with spouse & daughter)

5 References

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