

# Supported Decision Making: A Case for Change

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## Introduction

I wish to acknowledge the Toorubul, and Jagera peoples as the traditional owners of the land in the region in which we meet, as well as the Quandamookah people.

I wish to also congratulate Queensland Advocacy on this significant event. Also present today are two integral members of our South Australian Supported Decision-Making team. Cher Nicholson has come to the conference. She was the facilitator in our project; and Di Chartres had a significant role in the international research on which our work was based.

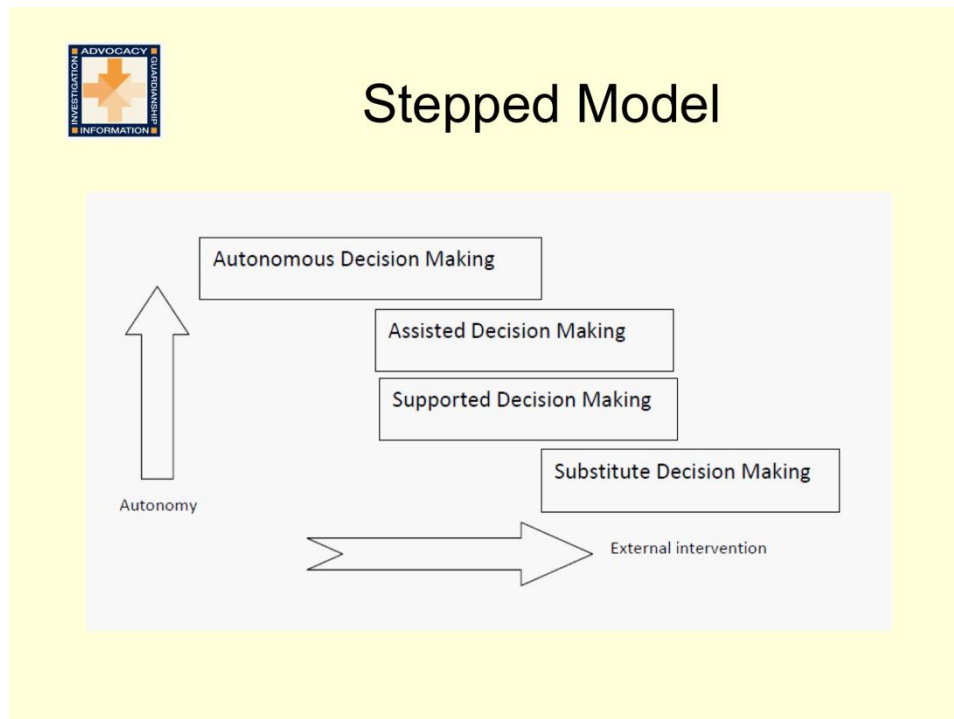
In South Australia, we completed our trial of Supported Decision Making late last year, and our thoughts have been about how the practice of supported decision making can be spread.

Today I would like to talk about how each of us might now apply the principles of supported decision making, either as people with disability making decisions or people delivering services to those with a disability. To do this, I will review some of the results of the South Australian trial, and the principles underlying the approach.

Our trial helped 26 people with a disability to establish Supported Decision Making agreements. These agreements involved a person deciding that they wanted to have support with decisions, choosing a supporter, and nominating what decisions the person wanted to receive support for. Potential supporters were given training and information so that they could decide if they were able to take on this role, and be able to provide support, and not become substitute decision makers.

## The Stepped Model

Our approach was based on a stepped model of Supported and Substitute Decision Making, first developed in 2009 and modified in 2010. The full model is on our website. This slide is a simplified version.



On the Y-axis, there are increasing levels of autonomy and personal authority and the X-axis represents increasing levels of intervention in the lives of citizens by government or others in a person's life.

The theory behind all stepped models is that if a necessary step is missing, people are more likely to 'fall to the right' so that the response of a system is excessive and disproportionate to need. So for example, if assisted and supported decision making is either not available, or not considered for an individual who might otherwise benefit from it, then guardianship is more likely. Without defining and articulating in a practical way what are these intermediate steps between autonomous decision making and substitute decision making, there is a greater chance that personal decision making rights will be lost; and also, the more intensive interventions, by making an individual dependent, may require a greater financial cost to deliver.

This model distinguishes what is described as assisted decision making from supported decision making. Using this delineation, all people have an obligation to provide assistance when involved in a transaction with a person who needs this assistance. This assisted decision making is a responsibility for disability workers, health workers, bank workers — whoever. In contrast to assisted decision making (applying this description), supported decision making occurs when a third person is invited by the

person who has a disability to support their decision making, attend meetings, communicate decisions and perform other tasks associated with decision making.

### **Overcoming attitudinal and environmental barriers**

Given that to some extent decision making is dependent on other people, for all of us, it is reasonable to ask why do we need to define supported decision making as an intervention and why we cannot retain a more traditional dichotomous model: having autonomous decision making for people with legal capacity and substitute decision making for those people who do not, and leave it up to individuals and their families and friends to sort out what happens in between.

The answer to this, I think, derives from our modern understanding of disability. From the preamble of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), State Parties recognise that disability results from the interaction between persons with impairments, and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.

Supported Decision Making tackles these attitudinal and environmental barriers, whereas the conventional deficit models of mental incapacity have focused on the individual.

For example, with respect to attitudinal barriers, some participants in our trial had taken on board an incorrect and stigmatising assumption that they could not make decisions. This had been a lesson learned through life. When they were children, when they were adults, it was expected, it was habit, that others would make decisions for them.

For these people, the trial provided skills, practice and personal recognition of their decision making rights so that individuals could take back the personal authority that rightfully belongs to them. A year on, an agreement is all some of these people wanted. Supported Decision Making for them is a process, a form of education if you like, rather than an ongoing dependency.

For others, the trial addressed an environmental gap in their networks — it made sure that supporters were prepared and able to spend time to talk about decisions and offer support, whereas before they were asked to take on this role, they may not have realised this was a need.

## Article 12 and personal change

So, in practice, I think it is worthwhile for each of us to consider: how should Article 12 of the UNCRPD change my life? how will it change my behaviour? in particular, what should I expect to receive or be prepared to deliver?

As a first step, I suggest that there should be an expectation that assistance with decision making will be available. If you are a provider of any service and need to discuss decisions, the question to ask is: what assistance can I provide? what can my service provide? For some, it may mean offering time: more time for a longer discussion, a second appointment. It may mean arranging communication assistance. For organisations, it may mean having plain English written and video material about services or choice options. These are just a few examples of how assistance might be provided to meet an individual's needs.

I suggest that presently, substitutes are called in when assistance could have been delivered.

If this is about to happen, then the question about assistance should be raised.

Then, if more support is required, can a third person help? I suggest that the step of involving another person, which is integral to supported decision making, is in itself a major step. On the one hand, it can uphold rights but on the other hand, if working with a supporter becomes an expectation of a provider of the client rather than a choice by the client, then this in itself could be discriminatory because the person cannot choose to turn up and deal with matters alone.

If a person has come alone to an appointment, they may have a reason, so to involve a third party in a transaction is a significant matter. Mostly in our study, people themselves were deciding whether or not they wanted support; for those who self referred, this was not an expectation of the service providers, but their own wish.<sup>1</sup>

So, even though a worker might suggest the need for support, the involvement of a supporter is a choice for the individual rather than an expectation of the worker, and if seen this way, this ability to choose can uphold freedoms and empower rather than be disempowering.

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<sup>1</sup> These issues are well described in the South Australian Law Society's Legal Capacity Guidelines (2012). (Available at <http://bit.ly/16RPoDy>) as they apply to clients' decision making when instructing a lawyer. The discussion though has more general use, as the principles are relevant beyond the client-lawyer interaction. Section IV of these guidelines describes the need to define the scope of third party involvement, to have such involvement cleared by the client, and to enable the client to retain control. It is necessary to confirm with the third party that they are not there to recommend or be persuaded of the best decision for the client, but to "...assist the client understand the choices and their wider impact on the client's life, because of the unique regard in which they are held by the client." The client's instructions are paramount.

Our study did not examine these ad hoc arrangements, but I believe that such arrangements need to be recognised and be part of our thinking, because otherwise it would be onerous and unrealistic to expect all support arrangements to be provided through a formal supported decision-making agreement of the type used in our trial.

Nevertheless, I suggest that the principles of support are the same. The decision about support needs to be made by the person who will be supported themselves — do they want support, and who will they chose to deliver the support. It is also important that the person called in to provide the support knows that they are the supporter, and not the decision maker. This is where literature about support and decision making, and can guide how to be a supporter might help<sup>2</sup>.

Such ad hoc arrangements could be set up in a quick and effective way, and within our community I would expect most supported decision making to occur in this way, because after all, decision making for all of us is depends to some extent on other people and such arrangements should not be impeded through formal structures and program.

Significantly, it means that for people here thinking about their own decision making, you should be able to expect assistance if needed, and if you wish to have a supporter to assist with a decision or attend a meeting, this will be facilitated. For service providers, these are actions that can be taken now in practice.

### Formal agreements

Yet there may be many reasons why a person might wish to formalise support with a formal agreement — to take the next step beyond the ad hoc arrangement.

In our trial, some people wanted a decision making agreement in order to gain skills and to claim back rightful authority. The agreement is a marker of this.

Others wanted to convert the role of a family member, say a parent of a young adult, from that of a substitute decision maker in their life, into a support role.

In other situations, supporters needed more training in their role, and a structure to guide conversations.

Then at a practical level, a person might have to make major decisions or a series of decisions, so having an agreement with a supporter makes sense because this support would be needed over a period of time. It is simply planning ahead.

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<sup>2</sup> A starting point for workers can be an explanation of the role of the supported person and the supporter that has been defined in trials but can be used in ad hoc arrangements. The Victorian Department of Human Resources has produced a booklet for use in the disability sector (see <http://bit.ly/13u6fyl> ). While it refers to the Victorian Charter of Human Rights and that state's legislations, principles can be applied to other jurisdictions.

One of the key hurdles for some people is choosing the supporter. Once the supporter is in place, decisions can be made but in the first instance, the big decision is whether or not to have support, and who the supporter should be. The process of putting in place an agreement, is assisted by a facilitator (in our case the project officer), to make this first decision before a supporter is in place. This can be another reason for choosing a more formal agreement rather than relying on ad hoc arrangements, because the same level of help in setting up the arrangement may not be there if it is more informal. My impression is that people are more likely to need this help, when there are environmental issues that might make the decision of selecting a supporter difficult — and by this I am thinking principally of conflict with family or conflict with providers that could make the choice of supporter difficult, or create problems in others accepting this choice once the decision is made.

While many people might find assisted decision making or an ad hoc supported decision making arrangement to be adequate, I suggest that before substitute decision making is invoked, a formal supported decision-making agreement should be considered as a least restrictive alternative. Supported decision making cannot be considered to have failed if the formal approach has not been trialled.

Within the range of supported decision making practice, there is yet another division — that between supported decision making that is recognised in legislation, such as in Canadian jurisdictions, and that which is not.

### **Statutory Recognition of Supported Decision Making**

Supported decision making can happen now. Legislation is not needed, and the lack of specific law should not impede practice — yet ultimately, legislative recognition can serve a significant role. My observation is that there are two levels of statutory recognition that are put forward. The first is in the form of principles that require decision-making support be considered before substitute measures are invoked. The second is specific recognition of agreements.

In Australia, supported decision making is recognised in the principles associated with disability reform. For example, the *National Disability Insurance Scheme (NDIS) Act 2013* recognises supportive relationships, and says that people with a disability should, where possible, make decisions for themselves. The rules for nominees place a duty on a nominee to refrain from acting if the person themselves could act or be supported to act.

Reference to the need to provide support before enacting substitute decision making can also be seen in the recently passed *South Australian Advance Care Directives Act 2013*. I also note that in Queensland, long before Australia ratified the UNCRPD, the

*Guardianship and Administration Act 2000* has a principle of maximum participation, minimal limitations and substituted judgement. This requires that an adult must be given any necessary support and access to information, to enable them to participate in decisions affecting their life. As I understand it, this principle must be considered by all those who exercise a power of function under the Act.

The challenge is to convert the principles into practice, so that assistance is offered, supporters are involved and if necessary, a supported decision making agreement is put in place. The problem with principles is that unless there is clear case law, there can be significant variation in the conversion of principles into practice. Assistance and support cannot be vague notions, they need to be operationalised or they may not really happen. Ideally, I suggest any professional or tribunal contemplating the imposition of substituted judgement should ask very specific questions about what assistance and support was provided, before seeking or making an order.

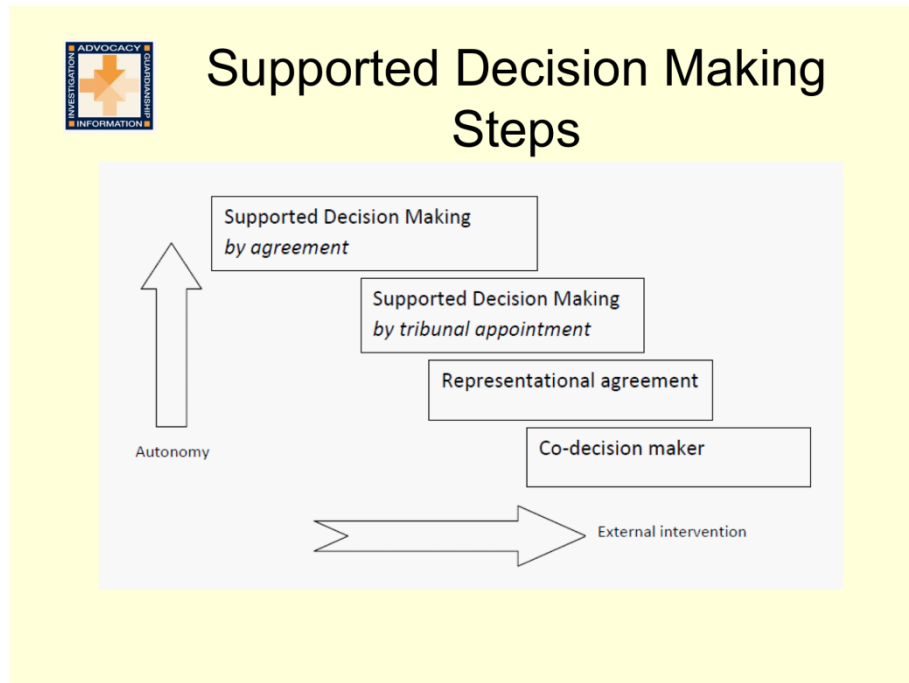
This then leads to the second form of legislative recognition — the level that does not just recognise principles, but incorporates specific provisions to recognise supported decision-making agreements, give status to the decisions made using these agreements, and codify the duties of supporters to the person supported.

As a side point, while we did not have statutory recognition for our trial, the agreements were seen as having value in themselves. Some saw them as a certificate of personal authority, which they did not have before. This was helped because coming from our Office, they had the Public Advocate logo and contact details. This type of auspicing authority might be fine for a small, closely monitored trial but ultimately, for widespread use, legislative recognition would be preferable.

For wider usage, legal recognition will be important. In many organisations, there are risk managers seeking to reduce liability from harm that might befall clients making decisions that may be risky. When there is doubt, a legally recognised guardianship order can allow for minimisation of risk to an organisations or transfer of risk. It is clear-cut and unambiguous. Legal recognition of supported decision making agreements would provide this clarity, because of the recognition of decisions and associated safeguards it might provide.

This diagram below is an expansion of part of the previous one, particularly looking at the spectrum of supported decision making practice. Supported decision making can be divided into arrangements made by agreement, with the person themselves appointing their supporter, and tribunal appointments of a supporter. In this schema the latter represents a greater loss of autonomy, and a greater level of intervention by the state. Ideally, this is an intervention that should be driven by the person themselves. Yet there may be people unable to appoint a supporter for whatever reason, but who might still benefit from support, rather than having a guardian appointed. Many of the people

in our trial had experienced a head injury. Needing to talk things over with a supporter, helped manage impulsiveness by putting in place a delay and time for consideration. One could imagine that in the future, a tribunal might wish to impose such a requirement as an alternative to guardianship.



There are also hybrids of supported and substitute decision making such as British Columbia's representational agreement, and Alberta's co-decision making arrangement.

We have been discussing such options with respect to supported decision making for older people with dementia. A person with dementia may experience a deterioration over say 5–7 years, and for much of this time can make their own decisions but might need support. Inevitably, in the final stages of the illness, a substitute decision maker will be needed but before that, either a separate supported decision making agreement could operate, or the person who is the donee of enduring powers of guardianship or attorney could be asked, or expected, to provide support as part of their role (for example, in future legislation).

Our trial was time-intensive as we developed our model, but the costs of this developmental stage of this work should not be applied to future practice. I firmly consider that a measured, commensurate provision of supported decision making services will be cost-effective.

### Supported Decision Making Practice and the UNCRPD

In doing the developmental work, we consistently went back to the UN Convention to help design the intervention, and problem solve. There is of course Article 12, on which the need for supported decision making is based.



## Article 12 Equal recognition before the law

Persons with disabilities have the right to recognition as persons before the law

Persons with disabilities enjoy legal capacity on equal basis with others in all aspects of their lives

### Persons with disabilities access the support they may require in exercising their legal capacity

All measures that relate to the exercise of legal capacity are safeguarded to prevent abuse; they 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 possible time and are subject to regular review by a competent, independent and impartial authority or judicial body.

In addition, Article 16 helped guide us in responding to safeguarding issues. Traditionally in Australia we have tended to conflate safeguarding with substitute decision making, because, I think, there has been an erroneous assumption that the risk of abuse and neglect rests with the person with a disability rather than their environment. In rights-based jurisdictions such as the United Kingdom and the United States there are dedicated adult protection services and coordinated responses defined in law or policy, that provide practical help to those at risk and are usually separate from guardianship systems.



## 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.



## Article 16 continued

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**.

This led our Office to undertake a separate project to describe what a rights-based adult protection response would look like. This work was focused on elder abuse and neglect in the first instance, but the principles also have application to the abuse of younger people. We also advocated in our state for a disability justice strategy, which is now being developed. Legal interventions wherever possible should be directed at the perpetrators of abuse through the criminal justice system, rather than the victims of abuse through guardianship and administration. These measures that are to create safer environments, I see can go in parallel with autonomy enhancing measures such as supported decision making.

Referring back to Article 16 helped our project committee manage these risk issues, as the article guides the breadth of measures needed to provide safety.

And Article 5 with its focus on reasonable accommodation, helped us focus on ensuring that the support arrangement was there to help the person with a disability, rather than becoming a convenient assistance to organisations. Even if a person has a supporter, there is still a duty on organisations to deal directly with a person with a disability where possible to provide reasonable accommodation. A supporter is not a convenient alternative to communicating with the client. I do not wish to sound cynical, but with any systemic interventions there can be unintended consequences and I think because of this, we should seek to address this upfront, rather than us all meeting again in 10 years' time to consider misuse of supported decision making and unintended loss of rights. We did not experience this problem in the South Australian project but we were aware of this potential issue.



## Equality and non-discrimination

### Article 5

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.

## Roles in Supported Decision Making

In the South Australian project, the supported person needed to be able to fulfil these requirements to enter into a supported decision making agreement.



## Supported Person

### **The person receiving support needs to be able to:**

Express a wish to receive support

Form a trusting relationship with another person(s)  
(supporter or monitor)

Indicate what decisions they may need support for

Indicate who they wish to receive support from for which  
decision

Express a wish to end support if that time comes

Be aware that they are making the final decision and not  
their supporter (take responsibility)

You can see the key elements. The person has to wish to receive support. The person needs to indicate which decisions they wish to receive support for, to nominate their supporter, and if necessary, be able to end the agreement.

This can be seen as a capacity test of sorts. Once the supporter has been appointed though, the whole process relies on a presumption of capacity, and there are no further tests of capacity. From that point onwards, capacity can be seen in the broadest sense as defined by Michael Bach<sup>3</sup>: respecting a person's will and preference. However, starting an agreement, I suggest, needs to be a practical process that can be readily understood by the participants.



## Supporter

### **The decision supporter needs to:**

- Respect and value the supported person's autonomy and dignity
- Know the supported person's goals, values and life experiences
- Respect the individual decision-making style of the supported person and recognise when and how support may be offered
- Form a trusting relationship with the supported person
- Be willing in the role of supporter, to fulfil their duty to the supported person, and not use this role as a way of advancing their own interests or any other person's interests
- Be able to spend as much time as is required to support a person make each decision
- Assist in the expression of that decision to others if required

These are the requirements for the decision supporter. This person is chosen by the person seeking support, but the nominated supporter should be able to indicate whether or not they can fulfil this role. For many reasons, our project did not wish to make the decision for the parties. It was not our role to vet supporters. When we first started, our research ethics committee asked us to undertake police checks on supporters, which we did for a while but sought their permission to stop. Ultimately, the self-screening process worked well. For example, when one female participant nominated a man who had been violent to her, that person, the potential supporter who had committed domestic violence, excluded himself.

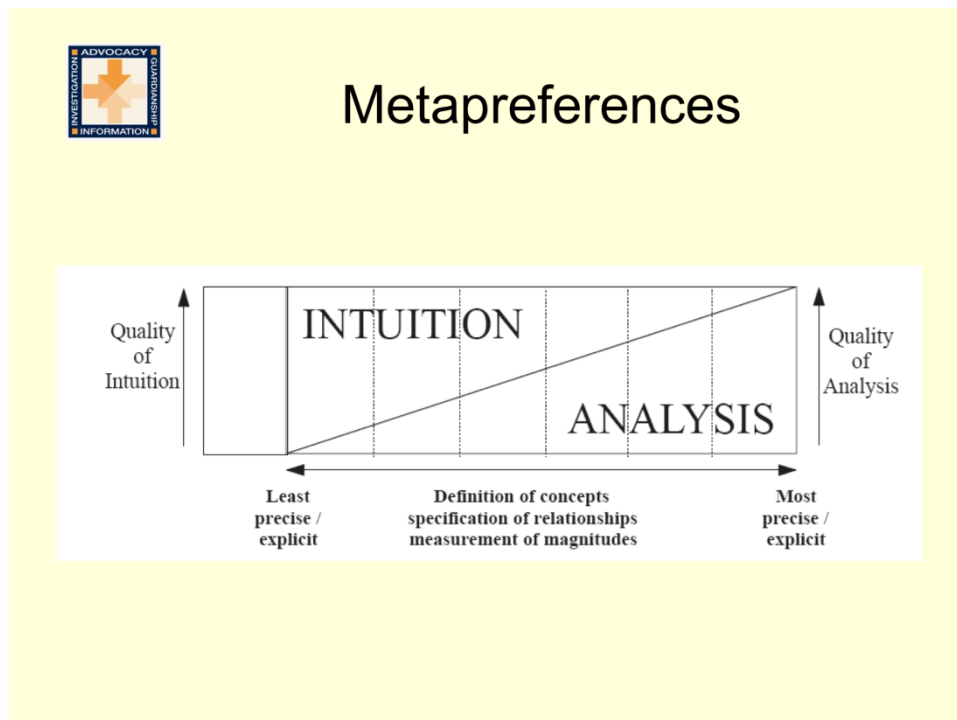
Ultimately, however, as a professional task, a professional facilitator cannot be party to an agreement that might be abusive, where there is already a misuse of power in a relationship, and a supporter whatever they might say, might wish to use the agreement to dominate another. We already know that advance directives can be used as an instrument of abuse. While the risk may be intrinsically less with a supported decision making agreement, because it does not give one person power over another, this can

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<sup>3</sup> A key presentation by Michael Bach can be assessed on this web link <http://bit.ly/14deuSq>

still be a possibility. In our trial however, there was no need for our Office to use this discretion not to proceed with an agreement. Educating participants worked well, and I suspect the need for a professional facilitator to withdraw from facilitating an agreement on ethical grounds would be rare.

With respect to supported decision-making practice, a key element is firstly helping the person seeking support to decide whether or not to proceed with an agreement, and secondly, educating supporters on their role.

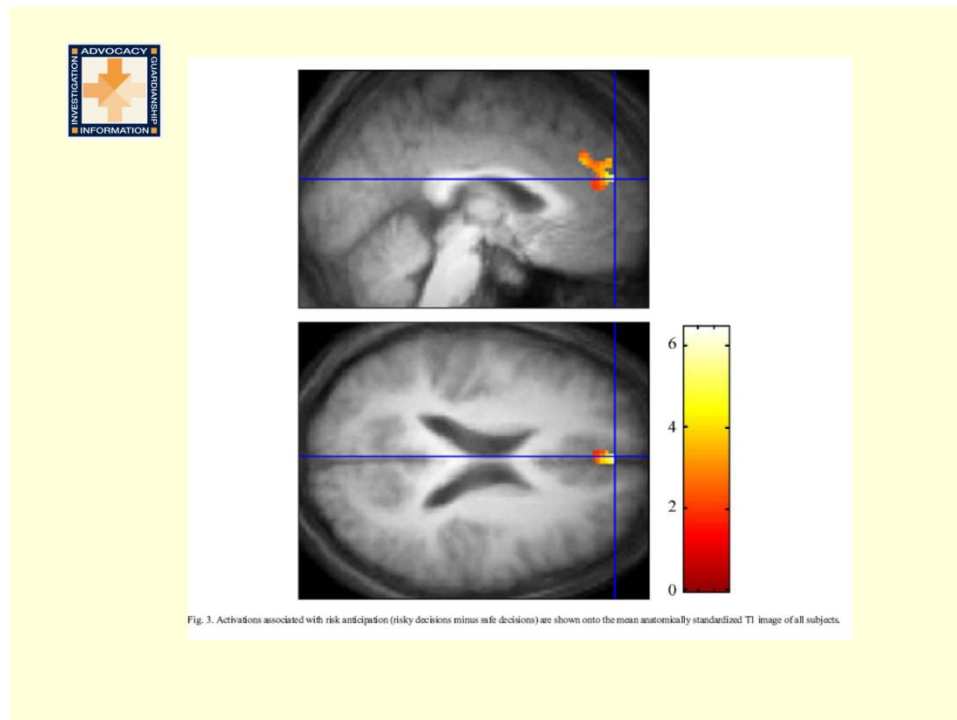


It is also relevant to consider a person's decision making style — what in the literature is considered a meta-preference<sup>4</sup>. For example, some people are more intuitive and others are more analytical. A supporter needs to respect the decision making style of the person that they are supporting, and not assume that they can substitute their own way of making decisions.

Work also needs to be put in context of the general decision-making research literature which considers the psychology, neurosciences and sociology behind decision making and is informed by work in economics. The next slide is a combined functional MRI of 19 subjects undertaking a card-based psychological task that assesses risk taking. It demonstrates activation of the medial frontal cortex associated with risky decisions<sup>5</sup>.

<sup>4</sup> Dowie (2002) used the term meta-preference – see Dowie (2002) The role of patients' meta-preferences in the design and evaluation of decision support systems, *Health Expectations* 5, 16–27. This is the source of the intuition–analysis diagram.

<sup>5</sup> From Fukui H, Murai T, Fukuyama H, Hayashi T and Hanakawa T (2005) Functional activity related to risk anticipation during performance of the Iowa Gambling Task, *Neuroimage* 24: 253–259. This image has been



Literature on shared decision making in health demonstrated the need to improve the way information is communicated to people generally. Surveys have shown that health literacy is impaired in 16%–47% of the population. In a 2006 Australian survey, only 41% of adults were assessed as having adequate or better health literacy skills.<sup>6</sup>

The following slides illustrate data from the South Australian trial, indicating who were the supporters and the decision made. More discussion about this can be accessed in a summary report on the SA OPA website (<http://bit.ly/18a6uil>). The decisions made in the area of health and lifestyle can be seen from these graphs. The changes in accommodation reflect accommodation decisions made as part of the trial.

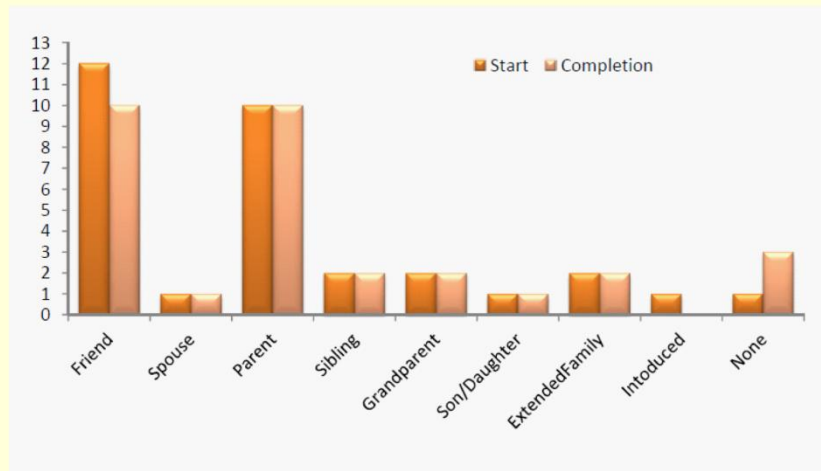
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created by subtracting the activity of “safe” decisions from “risky” decisions demonstrating the added activation in the medial frontal cortex.

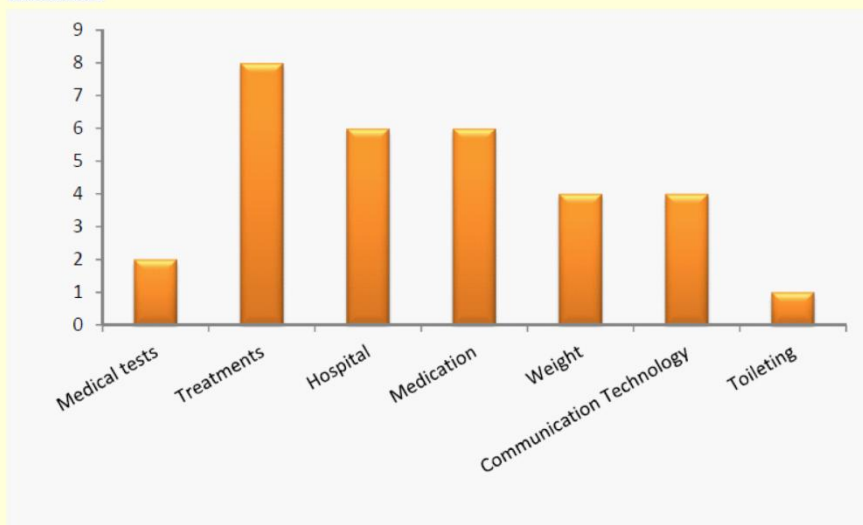
<sup>6</sup> The Australian Bureau of Statistics conducted the Adult Literacy and Life Skills Survey in 2006. More details are at <http://bit.ly/1751Ml4>



## Relationship with supporter

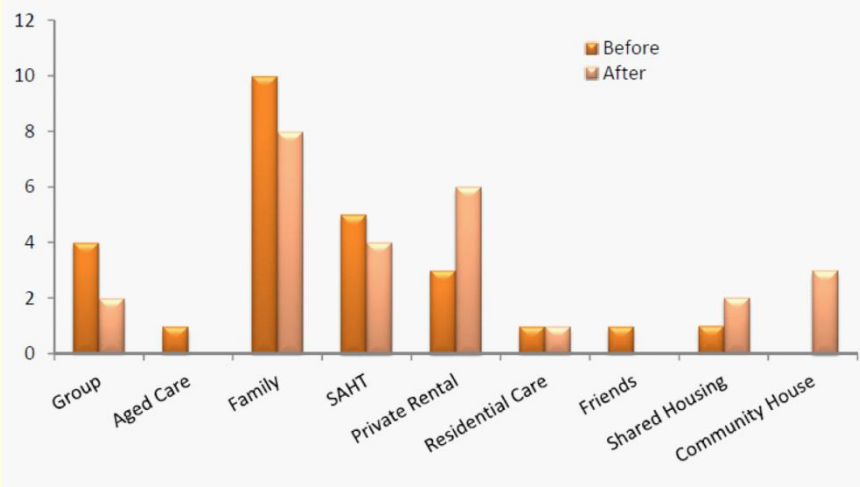


## Health decisions

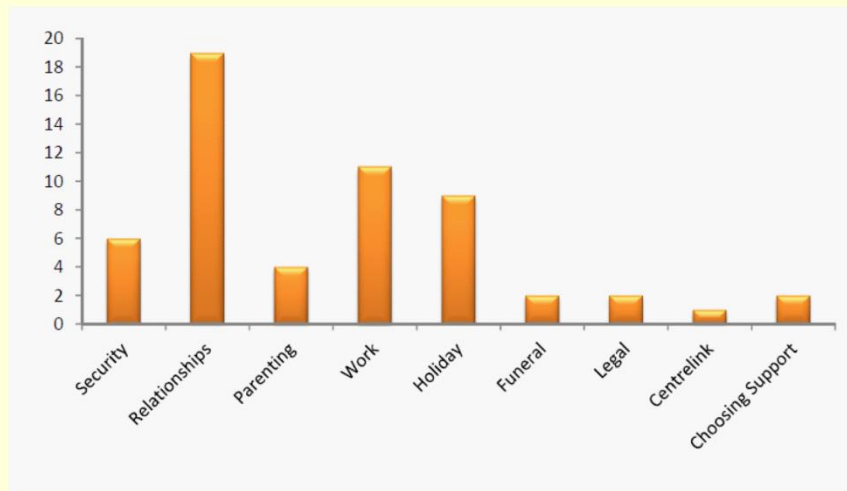




## Accommodation



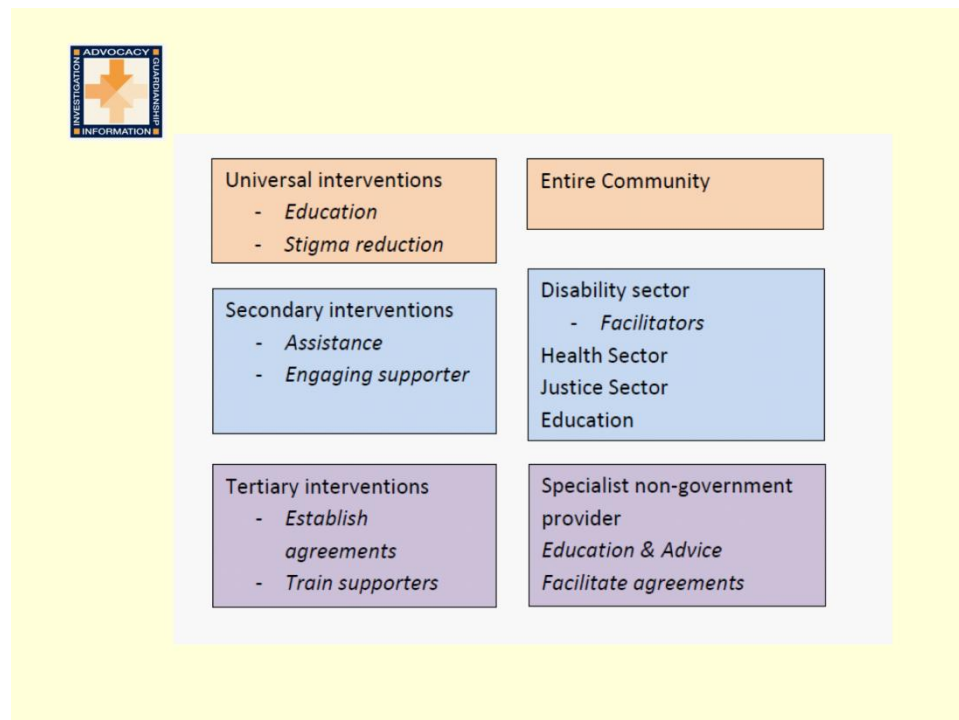
## Lifestyle



## A population based model of supported decision making

Our group in recent months has been discussing how supported decision making might become more widespread: how the work of our trial might spread so that supported decision making is more available to people who have a disability, mental illness or dementia.

In the next slide, I have put some of this thinking into a framework of primary, secondary and tertiary interventions borrowed from public health.



First, let us consider how the entire community might be engaged in upholding Article 12. If we accept that barriers experienced will be attitudinal and environmental, then tackling stigma and discrimination through broad public education could benefit many people.

As an idea, I wonder how future disability-awareness campaigns could be influenced and driven by the UNCRPD. In particular, an advertising campaign could be targeted to change attitudes and behaviours of the community more generally, grounded in the objective of upholding Article 12. This could create an expectation that all citizens will make their decisions, receive equal recognition before the law and more importantly, be offered helpful assistance by the community as they work, study, shop, engage in recreation — assistance that is useful, that is free of condescension and delivered in a rights affirming rather than begrudging way.

What might such a community awareness campaign look like?

Then, at a secondary level, there are human services professionals, people involved in the justice system and other people who might deliver a specialised service to people with a disability. This group might help individuals set up supported decision making arrangements, either on an ad hoc basis to help deal with a particular human services or justice issue or as an agreement to be used on an ongoing basis.

At this time, practitioners who have a role to facilitate individualised funding agreements through either state disability systems or Disability Care Australia could incorporate supported decision making into their work. This is happening with individualised funding for adults in South Australia.

To enable all users to maximise their control over the disability services they receive, assisted and supported decision making could be offered to help people develop disability support plans and choose where disability dollars allocated to them are spent.

These personal plans involve big decisions. As you would know, deciding about personal support services can first require a person to make significant decisions about personal goals, and where a person will live.

Then finally, there is what in the future might be the sub-specialist supported decision making sector, a sector that is yet to exist at this time, or comprises a few individuals involved in trials. I suggest that this sector, once established, need not be large. It can give advice to those operating at the secondary level, as well as directly assisting people set up agreements, who do not have contact with other services mentioned at the secondary level. I suggest that such a program could work out of the non-government sector, but this would need to be from an organisation that does not extensively deliver other support services, because of the potential conflict of interest that could develop if a person is being helped to choose between services. This could be a small NGO modelled on the work of Nidus in British Columbia.



## Acknowledgements

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*Margaret Wallace*

*External reviewer and commentator*

*Barbara Carter*

*John Chesterman*



Thank you. I hope that I have been able to describe a case for supported decision making. These are the members of the team. These are the committee members during the trial. It comprises members with a lived experience of disability, and staff with service provider, academic and legal experience. Cher Nicholson was our project officer for the trial, and Heather Linton our peer educator. Funding was provided by the Julia Farr MS McLeod Benevolent Fund.