

SUPPORTED DECISION MAKING IN AUSTRALIA

Presentation Notes

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Introduction

Welcome. Thank you for the kind invitation to be here. I would like to acknowledge the traditional landowners of the land on which we meet and their link to the land.

The first part of this presentation was initially delivered at the *Rights, Responsibilities and Rhetoric* conference in Adelaide in early October. It was this presentation that I was invited to repeat here.

I have added a second part that looks more closely at the technical aspects of the arrangements for Supported Decision Making. As you now have your review of the *Guardianship and Administration Act 1986* under way, I have also considered why Supported Decision Making should be underpinned by law reform.

Article 12 of the Convention has brought into sharp focus the possibility that Supported Decision Making can replace Substitute Decision Making in many situations. Because personal autonomy and self-determination are fundamental, there is no debate that it is better for people to make a decision for themselves, rather than have a decision made for them.

Where there is debate, is how far the guardianship system in Australia needs to move to comply with Article 12. Experts are working now, both internationally and in Australia, to interpret the legal aspects of the Convention as it applies to both the Commonwealth and States.

One view is that our guardianship system overall is already a good one in Australia and basically complies. Tribunals are very cautious about appointing substitute decision makers. For a long time, tribunals have sought to maintain informal arrangements and pursue the least restrictive option.



Presentation to OPA, Victoria

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Outline

Part 1

- Article 12 of the UN Convention
- Stepped Approach to Supported and Substitute Decision Making
- Example of Supported Decision Making

Part 2

- Redefining capacity
- Supported Decision Making Agreements

However, the tenet of Supported Decision Making is not to rely on nebulous informal arrangements, but to be very clear about what is being offered in the way of support. The United Nations Secretariat suggests that resources could be reallocated from guardianship to Supported Decision Making. Generally, we do not have these structured support systems here in Australia. There is a gap. This gap might be filled by formalised support that may come from the community — it might be a group of trusted friends, or family might be appointed as representatives to assist a person to make decisions, or it could come from professionals working in the system.

In this presentation, I will recap Article 12 of the Convention, and then look at the continuum of Supported and Substitute Decision Making. Accommodation will then be used as an example. Nearly all people want a home, and then will need support services so they can live in it. A decision to have a home may seem unrealistic, when all the system can offer is a supported residential facility or a nursing home for a young person. Yet this is a sign of the incapacity of our system to deliver, not a sign of decision making incapacity of the individual.

Supported Decision Making is also likely to take time. It can take time to communicate, to understand, and this may require a number of meetings.

The Supported Decision Making agenda also links with key international movements to have individualised funding and to better connect people to their communities. With individualised funding, a person who has a disability makes their own decision about what services are purchased with the dollars the government provides.

With respect to community connection, it is about the creation of new social networks when existing networks do not exist — such as the circle of friends. People are visited, they have support, and these people might then be members of the group who are supporting decisions. Professionals still have a role in training and oversight.

Article 12



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.

These are the items with which you will be familiar. They include enjoying legal capacity on an equal basis with others, and a requirement that persons with disabilities will access the support they require to exercise legal capacity.

In considering what we do now and how it might change, it is possible to be defensive. I know very well that the current systems of Substitute Decision Making are full of very good professionals, who are driven by rights, by freedom, by autonomy, and who want to make sure that people get the help they need.

Yet we all work within a system and the law. No matter how well we do our jobs, how much we want to fight the good fight to help people retain independence and fulfil their goals, we are actors in a system with limited options. There may not be an established funded system of Supported Decision Making. The only option might then be a Substitute Decision Making appointment. In current systems, appointed guardians often use Supported Decision Making approaches, and can do this well. Yet, because of the very nature of the guardianship appointment, the final decision is seen as that of the guardian, not belonging to the people themselves. If a form is to be signed, it will be the guardian who will sign off.

Similarly, if the day-to-day services on which a person relies for support and accommodation are limited, this may lead to a greater reliance on Substitute Decision Making. For example, people who have behavioural disturbances secondary to an intellectual disability can respond well if they are cared for in a calm, spacious environment, with sufficient care staff, and have psychological input. Supported Decision Making will work well. The same person living in an unsuitable group home or institution that is busy, cramped, without enough staff, may not only be seen as requiring guardianship but could experience physical and chemical restraint.

We work in a paradox. I wish to illustrate this with the following quote from Terry Carney:

At the heart of the jurisdiction is a contradiction. The ideology of freedom is linked to a set of legal tools to restrict freedom through the appointment of substitutes. Guardianship laws use a modern rhetoric of personal rights promoting autonomy, fostering independence, and assisting citizens to participate in social life. And yet the main task of guardianship forums is to strip citizens of rights, entrust proxies with the exercise of legal decision-making, and sometimes authorise incarceration through physical and chemical means. The strange paradox of using coercive forms to achieve emancipator purposes raises practical questions about what could possibly constitute successful intervention in this Alice in Wonderland world?

We can recognise this paradox, and value it. It is fortunate that guardianship work is done by people driven by the principles of autonomy and freedom.

However, Supported Decision Making is more in keeping with the rights focus of the jurisdiction. There is no paradox.

Retaining rights should not mean that either people themselves or the community will be at a greater risk. There are two particular points I would make about this. Firstly, I think we can accept that the decisions that are likely to work, the ones that will most fit with the person, will be the ones that people make for themselves, rather than ones made for them. In fact in current guardianship practice, while there may be a significant minority of decisions that go against the expressed wish of the individual, most are in accordance with what the person wants. Secondly, most failures to deliver services are because the system does not provide a service, rather than that services are refused. Once again, there is a critical link with advocacy.

There is still a need for Substitute Decision Making for situations of severe or profound impairment when there is risk. This need is likely to be less than the current use of these powers would indicate.

It is not possible for one part of the system to move unilaterally in the direction of Supported Decision Making. There are key levers of change — one is the legislation we work under, and another is the allocation of resources.

Modifying principles — Suggestions for the South Australian Act

The South Australian *Guardianship and Administration Act 1993* has the following principles:



SA G&A Act 1993 Principles

- (a) consideration (and this will be the paramount consideration) must be given to what would, in the opinion of the decision maker, be the wishes of the person in the matter if he or she were not mentally incapacitated, but only so far as there is reasonably ascertainable evidence on which to base such an opinion; and
- (b) the present wishes of the person should, unless it is not possible or reasonably practicable to do so, be sought in respect of the matter and consideration must be given to those wishes; and
- (c) consideration must, in the case of the making or affirming of a guardianship or administration order, be given to the adequacy of existing informal arrangements for the care of the person or the management of his or her financial affairs and to the desirability of not disturbing those arrangements; and
- (d) the decision or order made must be the one that is the least restrictive of the person's rights and personal autonomy as is consistent with his or her proper care and protection.

You will note the key substituted judgment principle, which is the paramount consideration in South Australia. This was, and still is, an advance on jurisdictions that purely focus on best-interest decision making.

With no current plan for a new Act in South Australia, the Office of the Public Advocate has suggested that changes could be made to the principles of the existing Act to bring it more into line with current approaches. These principles would include:



Additional principles

the decision maker must begin their consideration from a presumption of capacity, that is:

- (i) an adult will be assumed to have capacity to make their own decisions unless it has been established that the person lacks that capacity*
- (ii) mental capacity is decision specific. Capacity must be determined in relation to the specific function or task and the decision that needs to be made at a particular time,*
- (iii) a person is not to be treated as unable to make a particular decision unless all practicable steps to help the person to do so have been taken without success*

As you will note, they are:

- a presumption of capacity
- a clear statement that capacity is decision specific, and
- a requirement that all practicable support be given to the person to make their own decisions before they are considered unable to make those decisions.

It can be argued that the first of these two principles is already practised, and is affected by the Act in other ways. I can still see the benefit of a clear statement in using contemporary language.

The third principle is taken from the UK *Mental Incapacity Act (2005)* and can be used as the basis for ensuring that a person has been offered support to make their own decisions prior to the appointment of a substitute decision maker.

This is a starting point. Australia will inevitably move towards more substantial law reform and in this respect Victoria is first cab off the rank with its current review of guardianship law. Historically, Victoria has set the yardstick in this area in Australia, and it would seem that this might occur again given the terms of reference of the current review.

A Stepped Model of Supported and Substitute Decision Making

This is illustrated in the following diagram:



On the Y axis is increasing levels of autonomy and self- determination. Autonomous decision making is at the top, followed by Supported Decision Making.

On the X axis is increasing care and protection and increased intervention by the state. The appointment of a state official as guardian of last resort is illustrated here as the highest level of intervention by the state.

Some elements within the steps described are readily available in South Australia, and others not. More of these elements are available in Victoria but there are still gaps.

If there are gaps in a stepped model, then it is more likely that the system will move people to the right — increased care, protection and control.

Ultimately, this can be unsustainable. There is a need to have a balanced system because otherwise, with gaps, interventions will shift to the right with a greater loss of individual rights, possibly worse outcomes if a less restrictive option has been overlooked, and greater cost.

I suggest that this applies no matter how effective and well regarded a guardianship office is.

Supported Decision Making for Accommodation Decisions

This part of the discussion is about the link between service provision and decision making.

Who is making what decision for what reason is often unclear. Individualised funding is a model that can clarify different roles. I appreciate that Victoria has travelled much further down the path of individualised funding for disability services than South Australia and most other states.



Accommodation examples

- Supported accommodation
- Disability accommodation
- Home support services
- 24 Hour support for people who require mental health services
- Housing First
- “Non-preferred decisions”

Without such a system of individualised funding, decision making can be unclear because, in both disability services and mental health, the same organisation determines funding, which services are needed and who will provide them.

All of these factors can be blurred together. As an example, we might consider a real case involving an accommodation decision.

A middle-aged woman who had a pre-existing intellectual disability experienced a stroke, which affected her speech and movement. She was ready to leave her rehabilitation hospital but could not. She wanted to return to live with her frail elderly mother who had multiple physical illnesses. Mum wanted her back as well. It was decided by her treatment providers that this was unrealistic. It was concluded that mum could not care for her and she would need such extensive support hours that this option was considered unrealistic. The daughter was seen to be dependent on her mum. A guardian was needed to make the decision for her to be discharged to either a disability group home or a nursing home. As access to group homes was limited, discharge was likely to be to a nursing home in the first instance. An application was made to the Guardianship Board and a guardian was appointed.

The joint decision of the rehabilitation and disability services against home support was made for a mix of reasons. Ostensibly, it was because mum could not cope. However, the

reasoning for the decision was blurred by the cost of home support visits, and it really was not clear if it was made because of a professional decision about safety at home or a cost decision due to the number of hours required.

The guardian opted for a trial of the person's own preference. In conversation, it was clear that she knew what she wanted, understood the risks, and had a good understanding of options. She wanted to go home with help provided. With advocacy, an \$80,000-a-year package was allocated by the disability service, which happened to be the same funding that would be required for a residential placement with 24-hour support. She has now left hospital and is back home.

She is interested in a group home in the future, if the right place comes up, because she knows that mum is becoming more frail. She absolutely does not want to go to a nursing home.

How would this story differ in an individualised funding system with Supported Decision Making? There would be a separation of responsibilities about funding and the specific decisions about where to live, and the extent of support services. The funding decision would be made by the government using a resource allocation formula. The decision about what type of service and where to live would be made by the consumer. Because of her communication difficulties and the need to balance significant risks, some decision support would be needed and she would probably need someone independent to help with brokerage. Nevertheless, a substitute decision could be avoided through Supported Decision Making.

This is one example, but the same principles could apply to a person with a mental illness who wishes to return from a hospital to their unit rather than a supported facility, or a person who is homeless who would like to have a home rather than temporary shelter accommodation.

Of course, in the example I have provided, Substitute Decision Making could be said to have worked. The person concerned did not end up in a nursing home.

But this was at significant personal cost to both daughter and mother who were in a state of anguish about the guardianship order and what it meant. They knew the decision had been taken out of their hands. This created fear and anger. They pored over the reasons-for-decision document from the Board, and only decided not to appeal because the guardian was working for what they saw to be the right outcome.

This situation also illustrated the potential blurring of decisions about support needs versus resource availability. Systems of individual funding are objective. There may be debates about the formula, but once set, the number of dollars allocated will be the same, irrespective of who else may have been just allocated a package, or the state of the disability services budget for that month.



Individualised funding

- Stainton (2008) puts forward the following working definition –
“...funding allocated directly to an individual or in the case of a child their parents or legal guardian, to provide the support necessary to meet disability related needs and to assist individuals to become contributing citizens. It has two fundamental characteristics:
The amount of funding is determined by direct reference to the individual and/or family’s specific needs, and aspirations;
The individual and/or their family determine how funds are used to meet those needs eligible for funding.”

Section II: A More Detailed Discussion about Supported Decision Making Concepts

In the next section, I wish to revisit some of the concepts in more detail.

- *The different approach to mental incapacity needed to facilitate Supported Decision Making.*
 Generally, a broader definition of capacity is required. Such definitions recognise “personhood”, the wishes and desires of the individual, and the trusting relationship they have with people in their network. They are not the conventional legal definitions of capacity, which are narrower, and can be used to take away the rights of individuals. The use of such definitions to declare a person incapable may not meaningfully reduce risk for that person, but instead may address the risk management needs of provider organisations.



Decision Making Spectrum

- Autonomous
- Assisted Decision Making (meet existing legal capacity tests)
- Supported Decision Making (requires a new definition of capacity – would fail to meet existing capacity tests)
- Substitute Decision Making
 (Rep agreements – supported and substitute)

- *The need for legislation.* Does Supported Decision Making require its own legislation or is it something that can be practised outside of legislation? In South Australia, we are developing the plans for a small pilot program of Supported Decision Making that will be rolled out within our existing legislation. Victoria, with its current review, has an ideal opportunity to consider the need for a Supported Decision Making Act.
- *The need to have designated adult protection functions in Australia.* Other countries have integrated systems of adult protection for vulnerable people. The emphasis is on vulnerability rather than incapacity. For example, a physically frail aged person may be intimidated and exploited, even if they have capacity. The focus is on making communities safer, and avoiding the need to take away decision making rights from the victims of abuse or neglect.
- *British Columbia’s Representation Agreements.* This will be specifically discussed, as these agreements, although focused on providing Supported Decision Making, also

allow Substitute Decision Making. Is this the start of the slippery slope, or does it just make sense that if a person is in a situation where Supported Decision Making cannot occur — for example, they are unwell in hospital — that a supporter steps up to make the substitute decision, rather than another relative?

The Decision Making Spectrum

A first key element is defining what Supported Decision Making is, and given that it is more desirable than Substitute Decision Making, how its use can be maximised.

This list is similar to the stepped table, but whereas the latter considered how decisions were made, by whom, and under what power, this list only looks at the type of decision making used.

Definitions of what is Supported Decision Making vary in the literature. This list has some of the commonly used terms.



Decision Making Spectrum

- Autonomous
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Assisted Decision Making

In Assisted Decision Making, a person has the capacity to consider a decision, the different options, weigh them up, and reflect on the outcomes. However, the person may need some help — it could be with communication, collecting the information, or talking through the options.

In this respect, Assisted Decision Making is not controversial. Some might consider it a form of Supported Decision Making because it does require additional support, but in reality, it is autonomous decision making by the individual. Others are providing help with researching information and communication but the person retains capacity in the traditional legal sense once these accommodations are made.

It is likely that some people who may be able to benefit from Assisted Decision Making are referred for guardianship now, particularly if they wish to make a high-risk decision that concerns service providers. One way of maximising the use of assistance is requiring, as a principle in legislation, that a person should be given all reasonable assistance in making a decision before considering the appointment of a substitute. This may alter the outcome — by forcing greater time and effort to be spent with the person who has the alleged decision making impairment. The assistance process can also work two ways, because in providing this assistance, a service provider will also get more information from their consumer about why they have made a particular decision, and this may offer risk-management protection to the provider, should something go wrong. For example, a service provider for a person with dysphagia, who wants to take food orally against advice (so that they can taste and feel the texture of food), may collect more information about the person's reasoning as part of this process. The organisation might then feel more comfortable in accepting risk when it is clear that the individual has understood the situation, and is prepared to take the risk for the desired benefits.

Supported Decision Making

The next level is Supported Decision Making. Once again, it is relevant to note that exact definitions vary. The list illustrated (see slide) defining a Supported Decision Making Agreement is based on a list from the small Canadian province of the Yukon.

As can be seen, the system is formalised. This is in contrast to the current informal nature of most decision support practice as it exists now in Australia.

The formalisation makes it clear who is providing the support. It is written down, and a plan could also be put in place.

Ideally, these agreements can be implemented before problems and conflicts develop. For example, when a person who has an intellectual disability reaches the age of adulthood, it makes sense to sign them up to a Supported Decision Making agreement at that time.

This is what happens in British Columbia.

It can be a way of indicating to all concerned — parents, family and friends — their new role in supporting the decision of a peer, a fellow person, rather than making decisions for a minor.



Supported Decision Making Agreement

- This is an agreement between two or more adults to formalize a support relationship
 - An adult can authorize a support person ("associate") to help them make decisions in all areas – personal, health and financial
 - An associate has no authority to make decisions for you – their role is to assist and support you to understand and make your own decisions
- (Yukon)

Representation Agreement

The next level is a Representation Agreement. This is the model pioneered in British Columbia (BC). It is in essence Supported Decision Making. However, as alluded to already, some Substitute Decision Making is a part of the Representation Agreement. This is why in this discussion it is considered separately. Much can be learned from the BC approach to capacity and support: however, there is an unanswered question as to whether, if adopted in Australia, the 'substitute' element should be part of such agreements, or for it to remain a part of guardianship, which has greater safeguards.

Historically, these agreements have been around for many years, and predate the UN Convention. Author Michael Bach warns about commencing on the slippery slope to Substitute Decision Making, as these new decision making vehicles are developed.

These agreements are more than Supported Decision Making, although this is the first duty of representatives. They work on the spectrum. The Representative Agreements can cover health, lifestyle and routine financial matters, although they commonly apply to health and lifestyle. Routine finances include receiving pensions, paying bills, and purchasing food and personal items.



Representation Agreement

- Supported and Substitute Decision Making
- Duties of a representative
 - Help a person make their own decisions
 - Make decisions based on the persons wishes, preferences and beliefs
- Standard powers
 - No up front test of capacity
 - Personal care medical care
- Additional Powers
 - Refusing life support, override your objections
 - Must be aware of what you are signing

There is no capacity test for a Representation Agreement. This approach is strongly based on a presumption of capacity for all individuals. In this context, seeking to determine capacity might protect the professionals, but limit the individual.



Representation Agreement Act 1996 s9

Test of incapability for standard provisions 8

- (1) An adult may make a representation agreement consisting of one or more of the standard provisions authorized by section 7 even though the adult is incapable of
- (a) making a contract, or
 - (b) managing his or her health care, personal care, legal matters, financial affairs, business or assets.

As you can see, the Act is specific that there is no test for capacity in the usual legal sense. This is encapsulated in section 9, as it applies to Standard provisions.

The Act does offer an alternative to the traditional capacity test. It is based on a person's will, wishes, and ability to communicate. There has to be:

- a desire for the arrangement
- an ability to demonstrate choice and preferences, and
- critically, evidence of a trusting relationship



Representation Agreement Act 1996 s9

- 2) In deciding whether an adult is incapable of making a representation agreement consisting of one or more of the standard provisions authorized by section 7, or of changing or revoking any of those provisions, all relevant factors must be considered, for example:
- (a) whether the adult communicates a desire to have a representative make, help make, or stop making decisions;
 - (b) whether the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others;
 - (c) whether the adult is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult;
 - (d) whether the adult has a relationship with the representative that is characterized by trust.

With an agreement like this, the person remains in control because they can amend the agreement, or revoke it if these criteria are met — the process is less restrictive than guardianship, and the aim is support, even though some Substitute Decision Making is permitted.

The proponents would argue that “personhood” is maintained — a person gets assistance and support, but does not lose their decision making rights.

The process also offers protection from abuse. A key protection in these agreements is the requirement in certain circumstances to have more than one person involved. There are usually one or more representatives, and there can also be a monitor, who has a specific role to act as a safeguard and ensure that representatives do their duty. A monitor can be optional but is required when the agreement includes routine management of financial affairs, although there are some exceptions to this.

The UN is suggesting that we look to British Columbia as an example. There is no doubt that these models can work very well. People and families routinely present to the non-government organisation Nidus that promotes and sets up these agreements. The approach is based in the disability rights movement, but can be effectively extended to older people, such as those in the early phases of dementia.

Another question that needs to be considered if we were to adopt such agreements in Australia is what the scope for such agreements should be. For example, in the Yukon, people who have declining cognitive capacity cannot make an agreement, whereas in British Columbia they are not excluded.

Representation Agreements can be used very effectively to support the independence and autonomy of a person with a disability, but they can also be misused. Parents can sign up an adult child and support them with decisions as they become adults, but in other cases parents have been known to “wave representational agreements around” at service providers as a way of exerting their own authority — to make decisions for their adult child in the same way as they would have when their child was a minor.

However, all systems will have the potential for misuse. It is also often the way that, working in guardianship offices, we are more likely to see the systems fail than when they work. In our own practice in Australia, we know that some people misuse powers of attorney, but we persist with them because for most people, it is better to have them than not. The same might be said of abuse of Representation Agreements. Overall, people should be better off having access to such agreements than not. This should not preclude very careful consideration of safeguards such as the use of monitors, legal obligations on the supporters to act in certain ways, and systems of registration of agreements.

Redefining Capacity & Presumption of Capacity

To conclude this section, the next two slides are from Michael Bach and define the broader definition of capacity.



Re-Defining Capacity – 2 steps

1. First and foremost, capacity is the ability, with assistance as needed, to understand the nature and consequences of a decision within the context of the available range of choices; and to communicate that decision, with assistance as needed.

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Re-Defining capacity..

2. Where a person may not be able to meet these tests even with assistance, capacity can also mean the ability to express one's intention and to communicate one's personhood (wishes, vision for the future, needs, strengths, personal attachments and field of care) to a trusted group of others chosen by the individual who, in a fiduciary relationship of trust, confidence and responsibility recognize the individual as a full person, and commit to acting on and representing that person's agency in accordance with his/her intentions and personhood.

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This clearly states the broader concept. Without being prepared to shift to such a broader concept, which focuses on each individual's goals and wishes, personal vision, strengths and attachments, Supported Decision Making would only be available to a limited number of people.

Closely allied to this is the importance of presuming a person has capacity. This presumption is needed, because without it, people with particular diagnoses or disability may be placed in a situation where, in their dealings with organisations and tribunals, they need to prove themselves in a way that we do not expect of citizens generally.

When capacity is considered a personhood-based capacity test, it is more permissive and empowering than the typical legal capacity test.

In practice in British Columbia, the more traditional tighter test is still required for certain decisions, but this applies when a representative agreement empowers a representative to make significant substitute decisions rather than act in supportive roles — for example, when a person gives a representative power in the future to enforce decisions, or make decisions against the person's expressed wish. For pure, Supported Decision Making, the broader "personhood" test is adequate.



Implications for us

- Presumption of capacity – means not unnecessarily applying strict legal definitions (the latter can be to manage someone else's risk)
- Providing support – require evidence that assisted decision making has been attempted
- Provide for supported decision making agreements – formal accountability of supporters
- Additional question – should supporters have limited substitute powers as well??

The next two items on the list — to look for some evidence that Supported Decision Making has been attempted prior to appointing a substitute decision maker and providing for formal accountability for people providing support — I would not consider as controversial. It makes sense that all efforts be made to provide for Assisted and Supported Decision Making prior to the appointment of a substitute (in the first part of the presentation, this was suggested as an additional principle for the South Australian Act). Similarly, if support arrangements are to be put in place, some form of written agreement can formalise them, and help ensure that supporters are accountable — particularly as many of the people who enter into such an agreement to receive support are vulnerable.

A counter-argument is that there should be no need for legislation to provide Supported Decision Making, because such support can be delivered informally without a legal mandate. Most of us make important decisions with the support of other people, so why should there need to be specific legislative provision for this to occur?

While this argument has some merit, in practice Supported Decision Making in a disability setting is an intervention that requires commitment and skill. The role of supporter is a highly responsible one, requiring an understanding of decision making, and a desire to respect the dignity and autonomy of the represented person, who might be particularly vulnerable if the supporter were to fail in their duties.

The last question on this slide is the one we have just been discussing in terms of British Columbia — whether or not new Supported Decision Making arrangements should also permit limited Substitute Decision Making. The potential positives and negatives of this have already been raised.

Supported Decision Making Legislation

One can argue that ideally, legislation should be created to encourage, promote and facilitate Supported Decision Making, as well as to provide some protections and accountability around it.

If, however, legislation is not in place, this should not be an impediment for promoting Supported Decision Making as an alternative to guardianship, given that most existing legislation seeks to use guardianship as a measure of last resort.

As already mentioned, we are developing a trial of supported decision in South Australia — there are enough provisions in our existing legislation for us to develop Supported Decision Making as a less restrictive alternative to guardianship, although it is not named as such.

Yet, to achieve large-scale change in the community, a Supported Decision Making Act can serve critical functions.

Firstly, it can recognise the autonomy and self-determination of individuals. Our communities tend to adopt a default position of assuming that a person with a significant



Supported Decision Making Acts

- Are needed to affirm decision making rights
- Recognise the duties of supporters
- Set guardianship in the context of supported decision making as a last resort

disability cannot make a decision. If personhood is to be respected, if peoples' intentions and wishes are to be listened to, then this should be stated by parliament. It then becomes the starting position that people are full persons with wishes and intent, and should receive support.

Secondly, legislation can make it clear that all persons can expect decision support. It has to be an absolute expectation. An analogy can be made with disability access — a person with a physical disability has the right to expect that they should be able to enter a public building. We make accommodations to ensure this happens. Decision support is another form of accommodation to ensure that people can exercise their rights. Just because a person has neither family nor friends to step into a support role, should not mean that they should then have to enter into a guardianship arrangement. Sometimes decision support will come from family and friends, and sometimes from others. This of course is where parallel initiatives to create 'circles of support' for people who might otherwise be isolated and socially excluded, can assist with Supported Decision Making by developing social networks.

Thirdly, Assisted and Supported Decision Making can be the objective of legislation, not the provision of guardianship per se. A "Guardianship Act" is set up to provide guardianship. There is an argument that rather than having guardianship legislation to establish substitute practices, it would be preferable to have Supported Decision Making legislation to establish support as the norm. Such an Act might then provide for guardianship as a last-resort intervention when all possible attempts at supportive decision making have failed.

Adult protection

At this point, it is useful to separate adult protection from guardianship. In Australia, we have developed a public guardianship sector, but have not developed a distinct adult protection sector.

In the UK and the US, there are adult protection strategies and approaches that extend beyond guardianship.

As noted in this slide, the UK has developed safeguarding practices. There are high-level agreements in each local area between health, social services and the law. For any adult protection issue, there is a local accountable officer either in hospital or in the community who will respond. Protocols are in place, and the development of these protocols has been in response to a national direction, with top-down expectations to deliver of Chief Executives and others in local services.

Adult protection is everyone's responsibility. It is not just the job of guardianship tribunals and offices of the Public Advocate. An adult protection paradigm has many advantages. Firstly, the focus is on vulnerability not incapacity. More people can be helped because in reality other groups can be just as vulnerable as people who have an incapacity, such as the frail elderly who may have full capacity but still be stood over because of their physical vulnerability and sometimes isolation, or people with a sensory disability. These groups can



Adult Protection

- Safeguarding practice in the UK
- High level partnerships as part of "No Secrets"
- Protecting vulnerable people
 - ..who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation

be helped in the adult protection vulnerability model, as opposed to the guardianship incapacity model.

Secondly, there is an emphasis on teamwork, partnership and local responsibility. This can provide more timely local responses. In contrast, guardianship systems are mostly centralised with a single tribunal, and guardians are based in either a single location or a limited number of sites.

Thirdly, the adult protection strategy offers a range of health, social service and legal practical assistance — using similar approaches that are used for people who suffer domestic violence.

The aim is to keep the person safe, and ultimately have a safer community for all citizens. If there is a need to pursue legal interventions, then these can be directed if possible at the perpetrator. In contrast, a guardianship response focuses the intervention on the victim of abuse. Adult protection strategy considers the entire system, attempts to modify external risk factors, not just the internal “decision making” of the victim.

Beefing up adult protection in this country need not necessarily be difficult or expensive. A first step is to put in place directives for local agreements and protocols. Other steps include 24-hour reporting phone lines. While in the US reporting of the abuse of a vulnerable adult is mandatory, this would be controversial in this country. If we were to do this in Australia, it could be sufficient to have non-mandatory reporting in the community, but mandatory reporting for people living in formal care. A final step is the employment of additional adult protection workers.

While none of this specifically requires legislation — it can in the first instance be policy driven — the debate in the UK has now turned to the need for specific adult protection legislation. As one elder protection advocacy group puts it, we have legislation to protect animals and children, but not to protect frail aged.

Whether through policy or legislation, developing adult protection responses is a good parallel road to follow to rolling out Supported Decision Making. Traditionally, we have tried to keep people safe from harm by taking over their decision making — we take control of the life of the victim of harm or abuse.

Adult protection legislation aims to make our community safer, and punish the perpetrator.

Adult protection is like many other areas of public policy that require good joined-up responses. Similar strategies that have already been successfully applied in these other areas can be applied to adult protection. A failure to do so may also encourage unnecessary guardianships.

Squalor is another example of the need for good links between local councils, health providers and housing. The significance of these figures to this argument is that while 70% of cases of squalor are associated with a disorder, 30% are not. It is not sufficient to focus only on possible incapacity in the person



Integrated services and partnerships

- Child protection
- Domestic violence
- Homelessness
- Disability services
- Mental health
- Community crime prevention



Squalor

Snowden et al, 2006
Annual incidence 0.5 per 1000

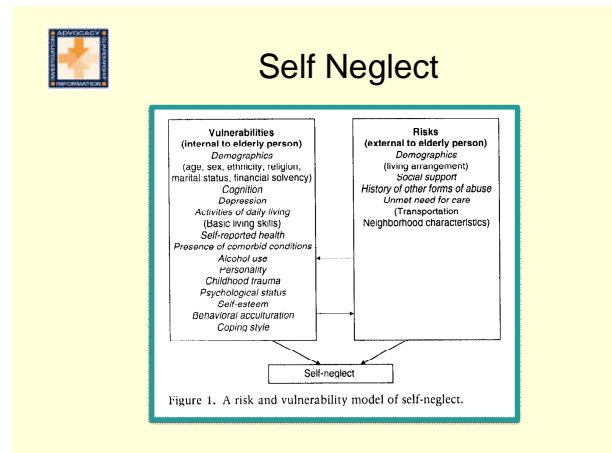
More common in men and elderly

Identifiable mental disorder	70%
Dementia or organic disorder	22%
Schizophrenia or schizoaffective	21%
Substance use disorder but no identifiable mental disorder	10%
Abused alcohol	27%
Developmental disorder	11%
Anxious avoidant	17%

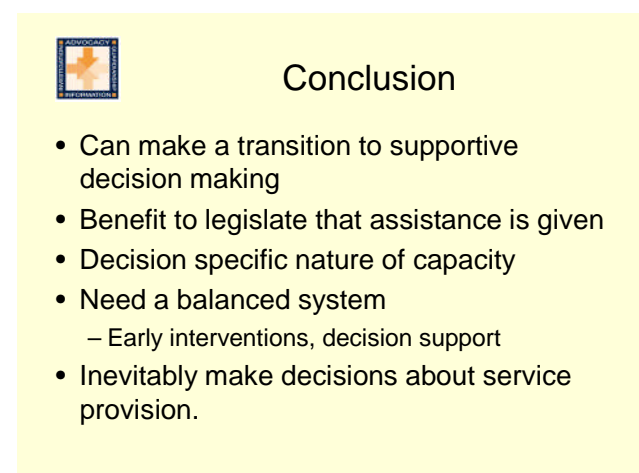
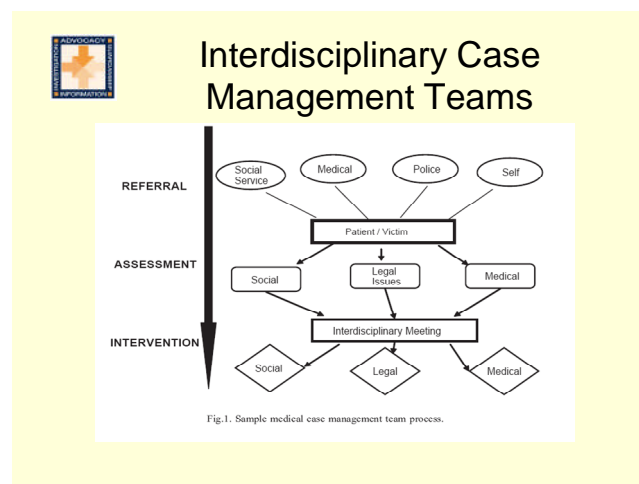
who is experiencing the squalor. A broad local response involving visits by councils, health workers and good social work casework can be key parts of an effective squalor response so that many cases may not need to hinge on invoking guardianship.

This diagram from a paper published last year looks at both the vulnerabilities and risks for self-neglect. This model highlights the need to address external factors such as poor transport, poor quality housing, and insufficient community support services, rather than focusing only on internal risk factors of the individual.

Responses need to be interdisciplinary, as demonstrated in this diagrammatic depiction of a US adult protection team response. The emphasis is on local partnerships and teamwork.



Arguably, even without the move to Supported Decision Making, good adult protection services are still needed. If there is a concern that measures to enhance the autonomy of vulnerable people will place them at risk in the community, then our efforts should be targeted at making the community safer, rather than intervening to control the life of the person at risk.



So in conclusion, Article 12 provides an opportunity for reform. In particular:

- To specifically provide for Supported Decision Making. This will need to be formalised with people trained to provide support (to act as representatives), and to be held accountable for this significant role through some form of monitoring, registering and reporting.
- By doing this, we can fill in the gaps in a stepped model which will determine the balance between Supported and Substitute Decision Making — with the aim to enhance autonomy and personhood.
- These changes rely on the use of a wider personhood-based capacity test — the ability to express desires, the wish to be helped with decision making, and to have trusting relationships. By using this wider test, significant numbers of people may be supported with decision making in the future, who currently have substitute decision makers.
- There is a need for system-wide change that ultimately will require legislative reform. This should not prevent efforts from getting under way beforehand.
- The movement towards Supported Decision Making is linked to other reforms that will increase the control that people have over their own lives, in particular individualised funding of disability (including psychiatric disability) services.
- This goes hand-in-hand with measures to improve community connections such as facilitating networks of friends for people who have a disability.
- Supported Decision Making can be promoted and facilitated by legislation. Arguably, this could be done with a specific Act aimed at promoting Supported Decision Making and autonomy.
- Finally, as just discussed, more work is needed to develop generic adult protection responses.