The Right to Safety and the SA Protection of Vulnerable Adults Project *Presentation Notes*

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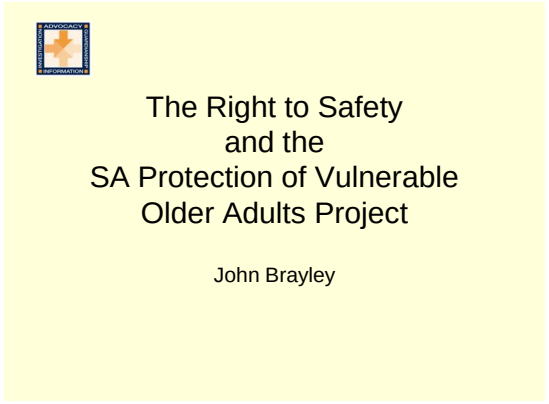
World Elder Abuse Prevention Day Conference,
Adelaide Convention Centre, June 2011

This text was prepared as the basis of a presentation delivered at this conference, organised by the Aged Rights Advocacy Service of South Australia.

Introduction



I wish to acknowledge the Kaurna people, the traditional custodians of this land, and the link to this land of the Kaurna people of today.

This paper is based on work undertaken for a collaborative project that is underway now in South Australia, which is seeking to define a rights based approach to keeping people safe.

What does it mean to have a "rights based approach". Will people be safer if we consciously redesign our systems based on human rights? The position our group puts forward is that a rights based approach can deliver greater safety to older people than our current system, while respecting the inherent dignity, and autonomy of individuals.

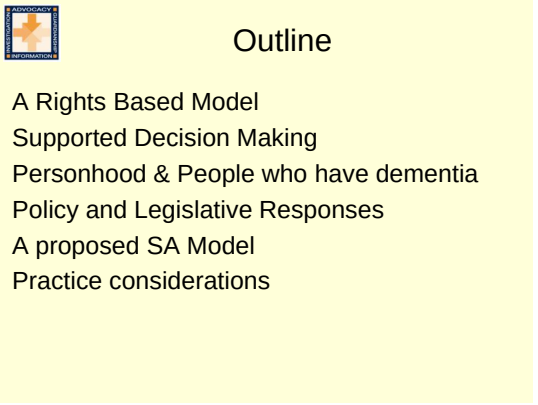
If Australia were to have a rights based system we think that our responses to adult protection would look more like those now in place in the United Kingdom, and North America, than the current service arrangement in Australia.

If a person is abused, a rights based system will direct legal interventions at the perpetrator. In Australia much of the legal effort for people who have dementia can be directed at the victim.

The focus of a rights based system is delivering practical, and if necessary immediate help to people at risk. This may be from a social worker, a police officer, aged care providers, health staff, local councils – all backed up if necessary by adult protection professionals.

In today's presentation, I will discuss the rights of older people as they can be derived from major human rights treaties. By defining these rights in any given situation, we can apply a rights analysis to what we as services plan to do. When we intervene to assist a person who is the victim of harm, what rights will be upheld, and which ones might be lost?

I will then discuss supported decision making. This is one part of a stepped model of supported and substitute decision making which I will describe. Our office is currently undertaking another project that is offering supported decision making to younger people with a disability. The rationale of supported decision making is that wherever possible it is preferable to support a person make their own decisions, rather than have another person make decisions for them. The same concept could be used effectively for older people– for example those who experience a dementia of mild or moderate severity. By ensuring support it may also prevent abuse.



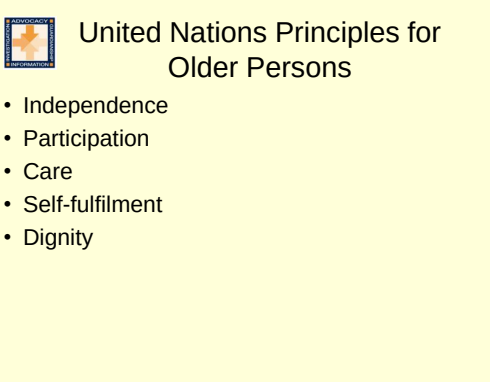
The concept of personhood is a familiar one to those who work in both the geriatric and disability areas. This respect for the individual can be a key determinant of what we do. Possible policy, legislative and practice responses will then be discussed.

This slide (opposite) lists the groups who have contributed to the advisory group of this project. It has been facilitated through our office with assistance from the University of South Australia. In addition to those listed, staff from mental health services for older people, general health services, aged and community services, non-government organisations and local councils have contributed to this work, and a range of volunteer and community groups have been interviewed. The work has been funded by Disability, Ageing and Carers Branch (formerly Office of the Ageing) of the Department of Families and Communities through, Improving with Age - Our Ageing Plan and Community Care Innovation Funds.

The project is not completed yet. We are still to have final meetings to draw conclusions together. What I am presenting today are a range of ideas linked to the project, and feedback on these ideas is most welcome.

Rights of Older People

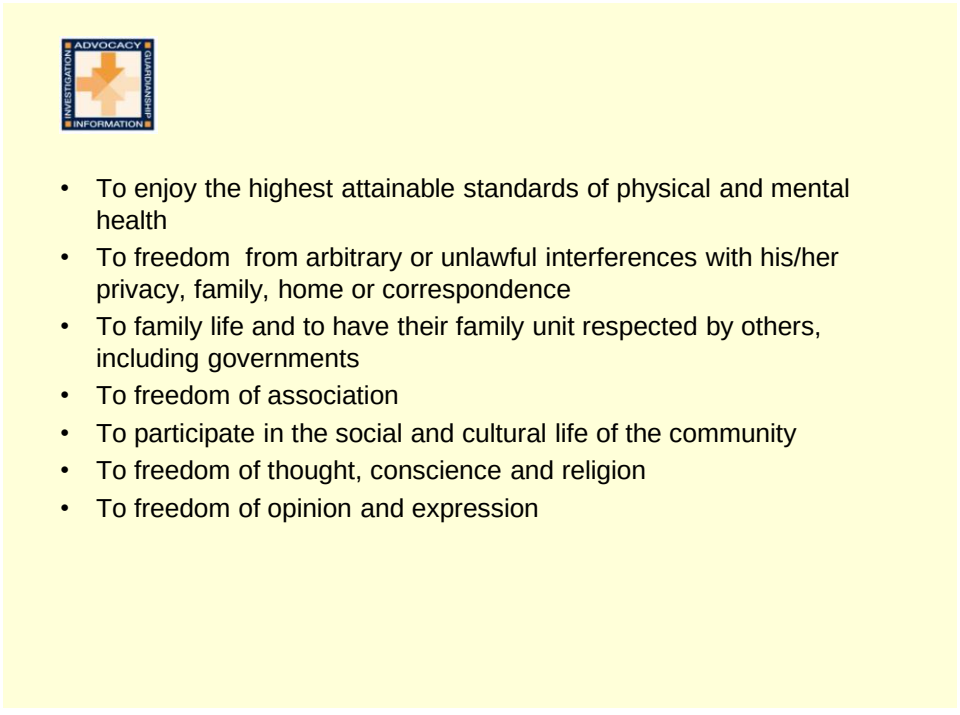
As it happens, there is not a binding international instrument that specifically captures the rights of older persons. There are available the UN Principles for Older Persons adopted by the UN General Assembly in 1991, but these principles have not been written in such a way to create legal obligations. The emphasis on independence, participation, care,



self-fulfilment, and dignity are nevertheless informative.

Our project has been able to go beyond this. On our team from the University of South Australia, is Wendy Lacey, who is a constitutional and human rights lawyer.

She has taken the major human rights treaties that Australia is a party to that might apply to vulnerable adults, and drawn up a statement of rights.



Wendy has written these rights as formal statements, in a way designed to empower the older person, and to create obligations on others to respect and protect these rights. She has stated

these rights fully but in these two slides (above) she has also in a simple way captured these fundamental rights and freedoms: dignity, humanity, self determination, liberty security, freedom from exploitation, and equal recognition before the law.

The list continues (on the second slide): the highest standards of physical health, mental health, freedom from arbitrary or unlawful interferences with privacy, family or home, to participate in the social or cultural life of the community.

This is the checklist for our adult protection policies and strategies. Can we maintain a freedom from abuse, while avoiding arbitrary interference in people's lives, or the unnecessary loss of recognition before the law – a loss which can occur with guardianship.

Gaps in our existing systems

Now to the present state – how are we performing in Australia, accepting that South Australia is representative of what happens nationally?

In beginning this work, our project officer Elly Nitschke spoke with many people working with older South Australians identifying the themes to be addressed, but also listing gaps to be closed.

It is important to acknowledge the excellent work that is already undertaken in this area in the aged care sector, in key bodies such as ARAS, in our own office, at legal services, and the policy leadership from the relevant State and Commonwealth departments. While this may be excellent work, we think our project illustrates something more fundamental is needed, and this is about a transformation to a rights based model so that good practice is offered to everyone in need.

Some of the gaps described to Elly include: uncertainty for community members about where to report abuse, uncertainty from health professionals about when to report abuse, variation in services depending on where a person lives, services waiting for a crisis to occur before acting, conflict between services, lack of suitable risk assessment tools, limited access to generic domestic violence assistance, and there is a particular gap in responding to older people in the community who are at risk but not currently in contact with a service provider for some other reason.

With respect to this last issue, some of our community services have become quite skilled at responding to elder abuse but this helps people who are receiving community service – nursing, allied health, cleaning, showering etc. How does a person not accessing a community service get assistance for elder abuse? How does the person next door get help for an elderly neighbour who is distressed and carrying a bruise if they are not currently being visited by a nurse or carer?

Rights based vs welfare based systems

So if we do not have a rights based system in Australia, what do we have? The alternative to a rights based system is a welfare based system. To paraphrase a definition used by authors Lynch and Cole used in another context (cited by Walsh, 2011), – welfare frameworks are based on "gratuities provided by a well resourced and compassionate society". In contrast a "...rights based framework enables marginalised and disadvantaged people to make claims against the state as a right."

A welfare based system will respond when it can, amongst its other priorities. In a welfare based system a recipient can feel lucky and grateful if they happen to get a response. A rights based system will respond each and every time, and will look for people to assist, because the responsibility of a rights based respose is to the community as a whole, not only to the people who are fortunate enough to be identified. A rights based system also does not depend on the person meeting a worker who happens to know about elder abuse, can recognise it and can be proactive, because this must be required core knowledge for all workers who deal with the aged.

Where rights based systems exist responding to elder abuse can genuinely be everyone's responsibility. Local social workers, health professionals, police and aged care services can work together, supporting each other. In such systems interagency agreements are in place so it is clear who responds. Funding agreements can include provisions for responding to abuse.

In addition, there also needs to be a specialist response to back up front line workers when required, but by the nature of the problem the frontline agencies will still need to remain involved. Telephone report lines can assist community members and professionals alike, and when necessary an investigative response should be available with legal powers to check whether people are okay or not okay. Currently though we have significant gaps in how the circumstances of an at risk person can be investigated.

Another key feature of these adult protection systems is that they can provide practical assistance whatever the cause of vulnerability. The help needed by a person who is physically frail but has capacity, may not be that different from the help needed for a person in the early phases of dementia.

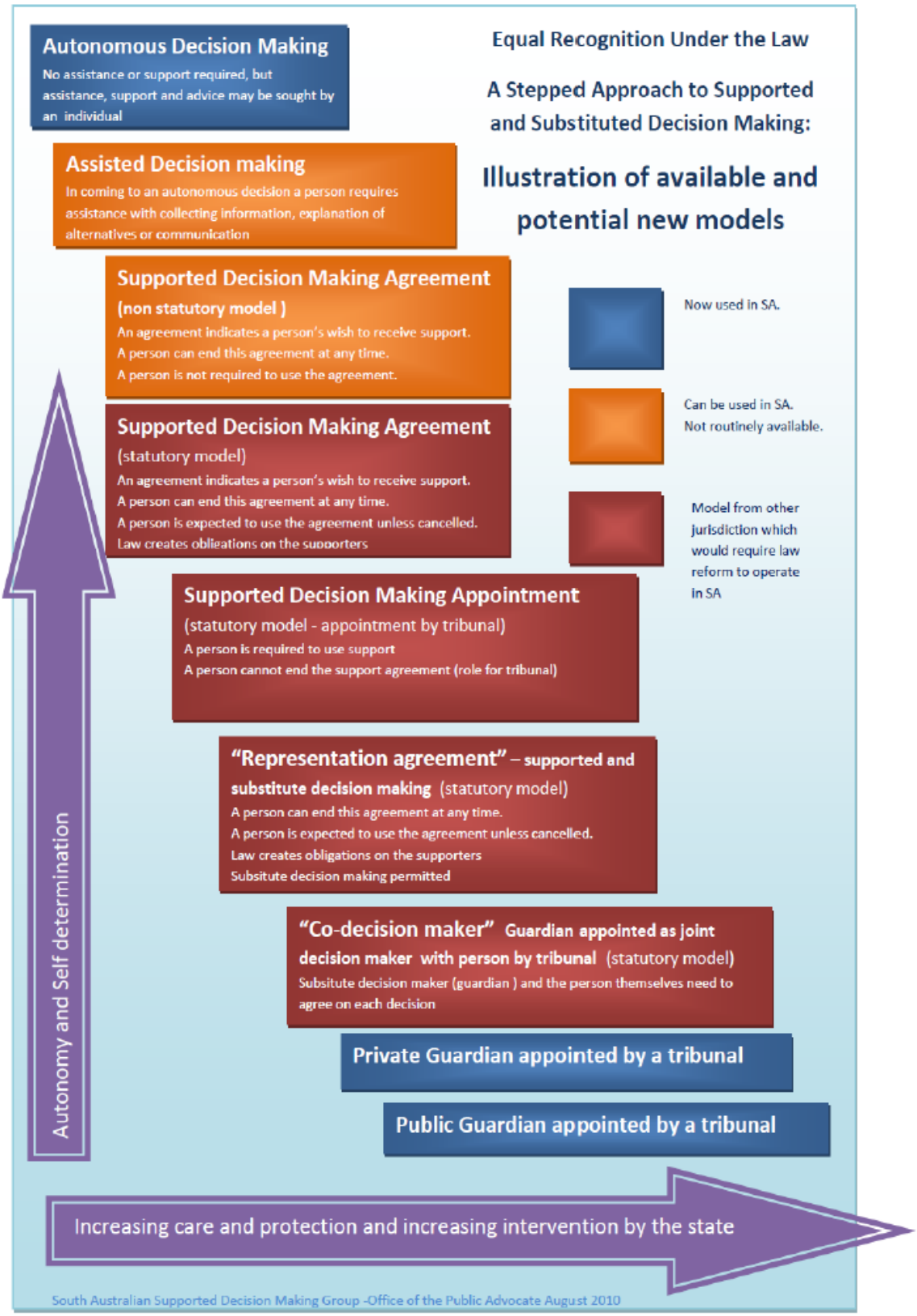
In Australia though, the response goes down two different pathways. Whether or not the person may be losing capacity can determine whether a referral is made to an advocacy service or guardian service.

We are yet to have a widespread generic adult protection response in this country that might assist vulnerable people, including those who have dementia. Instead Australian states have tended to develop Guardianship systems. There are times that guardianship is necessary, unavoidable and life saving. Yet because we do not have a good generic adult protection system, there are other times when a person with a developing incapacity is placed under guardianship as a way of getting an adult protection social work service. If there are gaps in a system those gaps tend to get filled by whatever is available, even if the solution is more intrusive or intensive than needed. The question is should it be necessary to lose one right – the right to make ones own personal decisions – to protect another, a right to personal safety. Particularly, if personal safety can be protected some other way.

In this respect without broader adult protection strategies to assist people who may be at risk because of dementia, guardianship is often the only solution available. Your might recall Abraham Maslow's "golden hammer" statement in 1966 "..it is tempting, if the only tool you have is a hammer, to treat everything as if it were a nail." We need a range of tools.

Supported Decision Making

I will return to the need for the universal generic approach later. However, it is worth talking more about supported decision making and then the topic of personhood.



This is the latest version of the Stepped Model of Supported and Substitute Decision Making, a way of depicting different levels of interventions. This was produced by our supported decision making project in August 2010.

On the Y axis is increasing levels of autonomy. On the X axis is increasing intervention by the state. At the very top is Autonomous Decision Making, with the highest level of autonomy, and the lowest level of intervention by the state. At the bottom is the appointment of the public guardian as substitute decision maker –with the lowest level of autonomy and the highest level of state intervention. I would note that even though guardianship is depicted in this way in our office we are proud of the work that we do, and we see a critical role for guardianship.

However the point of this diagram is to illustrate all of the other potential steps that might be available, but are not. The steps in blue are routinely used, the ones in orange could be used, but are often not, and the ones in red would require law reform.

I will not go through each step in detail but point out highlights. In this schema a person may need Assisted Decision Making. For example a person who has a memory or other cognitive disturbances may need repeated explanations, and aids in simple English, but if given this assistance may otherwise have the capacity to make a decision. All institutions in our community have a duty to provide this type of assistance when needed. This is a duty to provide "reasonable accommodation." This is also a requirement of the UN Convention on the Rights of Persons with Disabilities.

In the next step, Supported Decision Making, a person recognises a need for support and asks a family member or friend to provide that support. The person themselves still makes the final decision. The person will appoint the person who provides the support. For example a person in the early stages of dementia might choose to set up such an arrangement for a family member or son or daughter to assist with decisions in key areas. It is not a handing over of decision making power.

It has to be acknowledged that a person who has a progressive loss may be able to continue supported decision making for quite some time but eventually will need a substitute decision maker. Therefore it still makes sense to complete enduring powers documents while the person retains capacity to do this, but there may be a significant period that supported decision making can be used prior to the activation of enduring powers.

These are alternatives to guardianship. The United Nations disability office, in explaining Article 12 of the UN Convention on the Rights of Persons with Disabilities is explicit in describing supported decision making as an alternative to guardianship. Our current SA trial is focused on younger people who have a disability, but the same principles and approach could work with older people. I would suggest that for an older person having a carefully chosen and trusted decision supporter can be a protection against exploitation. Explicitly setting up such an arrangement could be a form of early intervention. It protects against isolation, and is innately respectful. Of course we do not have systems in place or the legislation to routinely do this.

The steps in red are examples of arrangements from different jurisdictions around the world. These include supported decision making arrangements that are formally recognised in law, that give obligations and extra rights to supporters, and arrangements where a tribunal can make an appointment of a supporter. In these situations a tribunal may chose not to appoint a guardian, but insist that a person use support. Another model is the co-decision maker model, an arrangement used in Alberta Canada. In this approach a person is appointed as co-decision maker with the person himself or herself. An analogy could be to the joint guardianship arrangements that are commonly used in Australia, but in this case one of the guardians is the

person subject to the decision making. Both participants need to agree on decisions, but if there is a disagreement the decision made by the person themselves is enacted.

Person Centred Care

The notion of personhood one has been a critical one in both the aged care and disability literature. In aged care Kitwood promoted the concept 20 years ago, and it still has an important role in gerontic nursing.

A lack of appreciation for the fundamental humanity of a person, can be the prelude to abuse, if empathy for the person is lost.

The work on personhood has also highlighted the valuing of the lived experience of people who have dementia.

It can reverse the dehumanising aspects of stigma.

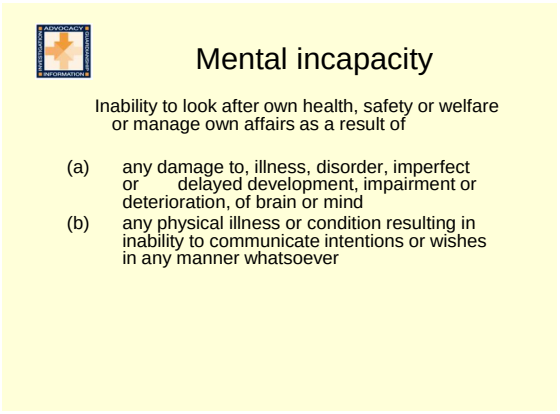
As an aside we see evidence of this stigma in the community generally. Hazel Hawke in 2003 said " I feel as if...my autonomy has been taken. I have an a illness. I've acknowledged it. I manage it as best as I can." She was also angry that Alzheimer's disease is perceived differently to other illnesses[1].

Then of course just this year Ronald Reagan's two sons were arguing as to whether or not their father had dementia when he was in the White House. He probably didn't but does it matter? While he had a poor memory, he was a President who knew his values, he wanted to stop nuclear war, and his presidency is now admired by many, including by people on the other side of politics such as the current President[2].

The work on personhood is complementary to the concept of rights. Respect, equality, and dignity go hand in hand with maintaining rights and being kept safe. In planning services in both disability and aged care, there is a view that instilling person centres values in services in itself can protect against abuse. It is reasonable to suggest that this idea – respect for the personhood of the individual - can also apply in the wider community.

I suggest that, for example, if an adult child is wanting to take mum or dads money, it will be more difficult for them to do this if they see mum or dad, as alive and vital, with ongoing rights,

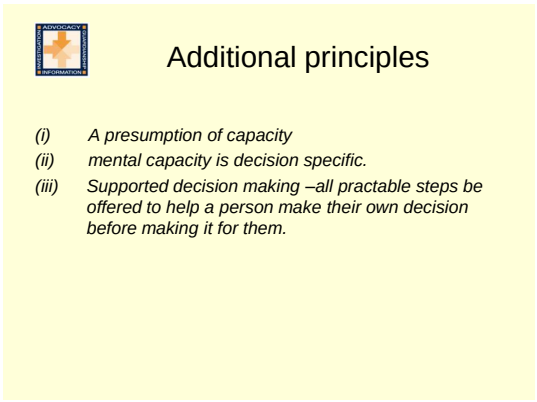
[1] Grattan M (2003) Hazel Hawke, I have Alzheimer's, The Age, http://www.theage.com.au/articles/2003/11/02/1067708071324.html
[2] Pilkington E (2011) Ronald Reagan had Alzheimer's while president says son, The Guardian, http://www.guardian.co.uk/world/2011/jan/17/ronald-reagan-alzheimers-president-son



with ongoing passions, relationships and feelings, rather than seeing mum or dad in a lesser way because of a diagnosis of dementia.

This is also where the stepped model can be useful. In respecting a person it is worth the trouble to have a range of options to choose from so that there is one that matches a person's needs, and retains as much autonomy as possible for as long as possible. This requires law reform. It gives choices to the individual as well as giving a number of options to a Guardianship tribunal.

In South Australia our current *Guardianship and Administration Act 1993* is nearly 20 years old. The way capacity is described is not consistent with our modern understanding of rights, the law, and medical science. You can see the broad definition in use in South Australia (slide above). It is an inability to look after ones own health, safety or welfare, or to manage one's own affairs as a result of a range of conditions.



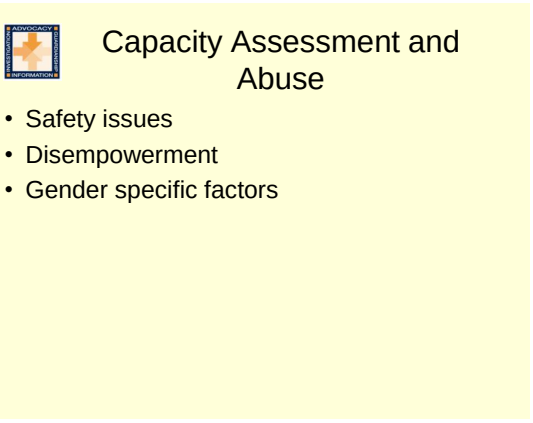
We could be more specific in our definition. The next slide illustrates some key principles that are commonly accepted in law, medicine and psychology, but could be stated explicity in our Act. One is a presumption of capacity. This is akin to a legal version of a recognition of person hood. A person should not need to constantly prove that they are capable of making the next decision as if they were a child. Now some would say that we already implicitly recognise a presumption of capacity already, but is this really what happens in practice? Secondly, as we know from both the common law and clinical practice, capacity is decision specific. Our law could state this. Then finally there should be a requirement to attempt to support people make their own decisions first? This is a requirement in the UK, and should be one in South Australia.

This gets back to the role of Guardianship legislation. I am arguing that guardianship should be limited in its application, and it should not be seen as the principle vehicle for adult protection for older adults who are developing dementia. If we have a recognised adult protection system, a protocol, a policy or even adult protection legislation this should take the front line, and this is more consistent with a rights based approach.

These arguments can be extended further. The experience of abuse can interfere with capacity assessments. A person who has been traumatised may appear cognitively incapacitated when they are not.

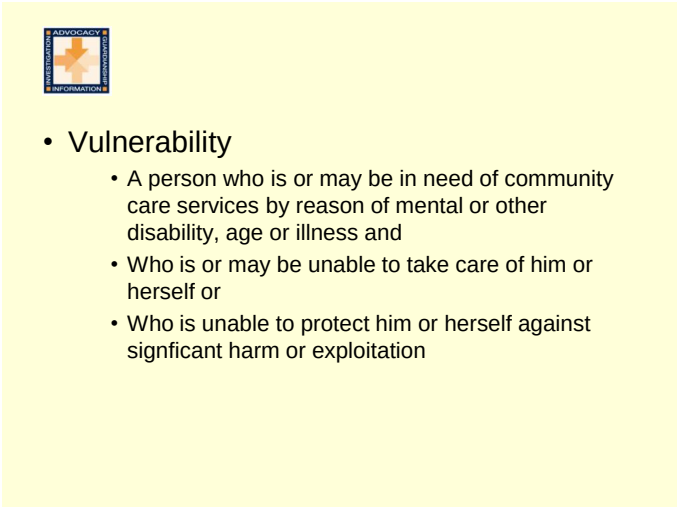
Two years ago O'Connor et al from British Columbia published a paper on the topic of assessing capacity in the context of abuse and neglect. They noted areas where a persons performance at assessment may be negatively affected by abuse.

The first is in the area of safety. Experts in the incapacity literature recommend assessing people with close family or friends present to alleviate anxiety. This could have the opposite effect if a person has been the victim of abuse and the abuser is with them when an assessment is made. A second area is one of disempowerment. A person who has been abused may have a sense of powerlessness and futility that can make completing an assessment difficult.



At its worst because of the impact of abuse, enduring powers donated to an abuser may get activated because of an assessment of incapacity when the person affected really needs to retain control.

These issue may put the concept of capacity in context. A person who has experienced abuse may already experience fear and shame, and the loss of the ability to make personal decisions may be a further loss of autonomy and self. Once again, if this is an unavoidable action needed to keep people safe, then it is also an unavoidable side effect or cost to get a necessary benefit. It is a different question though, if there were more alternatives available in our system of responding to people's needs.



The need to respond to vulnerability and risk

So if we are not going to rely so much on incapacity to afford adult protection what should an adult protection system be based on? Whereas guardianship systems focus on capacity, adult protection systems focus on notions of vulnerability and risk.

A vulnerability definition is wider than mental incapacity. The definition on this slide was established by the key UK policy "No Secrets". In recent years the term "adult at risk" has replaced the term vulnerable adult because of a concern that the term "vulnerable" may wrongly imply that some of the fault for abuse lies with the adult abused. In each local service area there are detailed agreements between services describing how they will work together.

The responses are based on vulnerability not capacity. In contrast in Australia there is an early of triaging of response down a guardianship route for people who have a cognitive impairment. In contrast with a vulnerability response, guardianship may still be needed but it is not first line.

Adults at risk

- Are unable to safeguard their own property, rights or other interests;
- Are at risk of harm; and
- Because they are affected by disability, mental disorder, illness or physical or mental imnfirmity, are more vilnerable to being harmed than adults who are not so affected.

On the next slide are definitions from the Adult Support and Protection (Scotland) Act 2007. For a person to be an adult at risk, they need to be at risk of harm caused by another person's conduct, or be engaged in conduct that might cause self harm.

This legislative framework then allows services to intervene when reports are made.

The use of the word "harm" in this definition is a deliberate choice to note. It is used as an alternative to abuse. The key focus is on of harm - whether it is intentional (and therefore easily recognized as 'abuse') or unintentional a person still needs protection from harm.

In speaking to stakeholders in South Australia there are mixed views about the word 'abuse'.

Our view is that it is important to accurately label abuse for what it is, so that it is clear to all that it is not acceptable. However there are times when it may be clear that a person is being harmed, but there may not be evidence for abuse. This could inhibit the making of reports.

There is also a need to respond to families under carer stress who need to be engaged, supported, monitored, and who need to come forward and reveal problems. This may be assisted with a "harm" definition.

As stated harm can be either intentional or unintentional. It is critical that we know about it, and that harm is responded to even if there is uncertainty about the motivation of the person causing harm.

I would note that in the UK there has also been a practice of undertaking serious case reviews to learn when adult safeguarding does not work. This is akin to reviews that are done here in child protection, and have had an important role in identifying problems.

A Universal Adult Protection Response

At this point it is worth going back to the types of strategies that our project is discussing, that are still to be finalised. This includes recommending a new policy focus on adult protection and a new definition of people at risk.

Universal adult protection response

- A code that defines "at risk" people and the obligations of services (general and specialist) to respond.
- Local working agreements similar to "No Secrets"
- An initial response to at risk people based on keeping a person safe not capacity.
- Telephone report, and investigation response

If this is agreed on, a wider group of people may in the future be assisted with a common response.

Local working arrangements are an obvious step. However in the medium and longer term if elder abuse is to be "everyone's responsibility" it cannot just be left to happen based on the level of interest of individual staff working in a particular geographic area. A requirement to respond and to train staff could become a routine part of funding agreements at all levels of government.

Existing domestic violence responses can also be used because there already are across service mechanisms in place such as the domestic violence gateway.

Early intervention, and collaboration will require information sharing. We have been looking at applying existing guidelines from child protection. However, to facilitate the sharing of information it helps to have a legislative backing. Whatever people think of mandatory reporting, it does give legal permission for client confidentiality to be broken to keep a person safe when a condition has been met.

We already have mandatory reporting in Commonwealth funded residential aged care. In a rights based framework the benefits of mandatory reporting can be justified, as it upholds a right to safety. The greatest concern is how a response can be provided when the reports come in, however we have heard today examples of how such mandatory reporting can work in the United States. Some people who we spoke to as part of this project were more concerned that there be a "mandatory response" rather than a requirement for mandatory reporting.

In this presentation I have suggested a broad focus on vulnerable adults, and a shift to the types of systems common in the UK and in North America. This follows themes that have developed in our project, which of course is yet to be finalised.

Countries such as the UK, US and Canada who have made progress in these areas either have a Bill of Rights or a Charter of Rights. The importance of a rights basis in designing effective practical systems cannot be overlooked, as even without a Bill of Rights, these rights can be upheld in policies and adult protection legislation. This will be considered further as the work of our vulnerable adults project enters its final stages.

Further Reading

Adult protection in England and Scotland:

Department of Health (2000) No secrets: guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4008486

Government of Scotland (2007) Adult Support and Protection (Scotland) Act 2007, http://www.legislation.gov.uk/asp/2007/10/contents

Further background reading on adult protection and rights:

Office of the Public Advocate (2009) Adult protection systems overseas, page 43 -47, in *2009 Annual Report*, Accessible at http://www.opa.sa.gov.au/documents/09_Publications/Annual_Reports/15_AR%202008-09.pdf

This provides more background on designated adult protection services overseas.

Office of the Public Advocate (2010) Stepped Model of Supported Decision Making, pages 107-109 in 2010 Annual Report, Accessible at http://www.opa.sa.gov.au/documents/09_Publications/Annual_Reports/16_AR%202009-10.pdf

This reference provides more details of each of the steps in the model that were not explained in detail in the presentation.

Walsh T (2011) Homelessness as a Violation of Human Rights, in *Homelessness and the Law*, Federation Press, Leichhardt.

Some of this paper's description of rights based vs welfare based systems, as put forward by P Lynch and J Cole, and applied to homeless, have been used in this presentation to consider the "right to safety" for older people at risk of abuse and neglect, and compare this with existing welfare models.

Personhood and Aged Care

Dewing J, Personhood and dementia: revisiting Tom Kitwood's ideas Older People Nurs. 2008 Mar;3(1):3-13.

http://www.ncbi.nlm.nih.gov/pubmed?term=Personhood%20and%20dementia%3A%20revisiting%20Tom%20Kitwood's%20ideas.

Assessing capacity within a context of abuse or neglect.

O'Connor D, Hall MI, Donnelly M, Assessing capacity in the context of abuse and neglect, J Elder Abuse Negl. 2009 Apr;21(2):156-69.
http://www.tandfonline.com/doi/abs/10.1080/08946560902779993?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%3dpubmed#preview