To investigate new models of guardianship and the emerging practice of supported decision making.

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Signed

Dated
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Introduction

On 25 February 2010 the standing committee on social issues presented a paper to the NSW Legislative Council on Substitute Decision Making for People Lacking Capacity. This report outlined a paradigm shift which is occurring in NSW and internationally in relation to people with disabilities. A new social model of disability has been embraced which emphasises ability rather than disability, capacity rather than incapacity and rights rather than protection. The report outlines a number of principles which are guiding this cultural change which include the presumption of capacity, the principle of least restriction and the promotion of supported decision making as opposed to substitute decision making.

Recommendation five of the standing committee paper was that the NSW government amend legislation to provide for the relevant courts and tribunals to make orders for assisted (supported) decision making arrangements and to prescribe the criteria that must be met for such orders to be made.

For those who work in the area of guardianship, such as myself, supported decision making is an exciting concept. Exploration of this area raises a number of questions such as: It is possible to support someone to make a significant life decision that they would have been unable to make independently? What does supported decision making actually look like in practice? Does the introduction of supported decision making reduce the need for substitute decision making? Would the models of supported decision making being used in other countries be transferable to an Australian context?

Within the NSW Public Guardian there has been limited access to information on how supported decision making is structured elsewhere and whether it has been successful in resolving the tension between rights and protection. This lack of information has been frustrating, and discussions in this area had created a desire in me to travel overseas and explore supported decision making further. From my reading in the area I understood that Canada and England had sought to address these questions very differently. I thought it would be very interesting to investigate and compare the different legislative frameworks that seek to enable supported decision making, and to meet people who were actually facilitating these processes. I also thought it would be useful to have firsthand experience of supported decision making models and be able to share this with guardianship offices and other relevant stakeholders in Australia.

I am indebted to the Winston Churchill Memorial Trust for enabling me to realise this desire to investigate models of guardianship and supported decision making overseas. I also wish to express my gratitude to the Department of Justice and Attorney General for supporting my pursuit of knowledge in this area. Finally, I am indebted to every person I met during my fellowship journey who shared their knowledge, experience and expertise so generously. I am hopeful that the information they shared, which is contained in this report, will be of interest to a number of stakeholders who are seeking solutions to the questions regarding the implementation of supported decision making.
Context

This report is written with a view to advising the NSW Public Guardian as to my experience of a number of models of guardianship, supported and substitute decision making in England and Canada. My conclusions and recommendations are written with this audience in mind. I hope this information is also of interest to other groups and stakeholders and look forward to engaging in dialogue with anyone who shares a similar passion about these important issues.

The NSW Public Guardian exists to promote the rights and interests of people with disabilities through the practice of guardianship, advocacy and education. The NSW Guardianship Tribunal appoints the Public Guardian as a guardian of last resort. Guardianship Orders in NSW are time limited and have specific areas of authority such as accommodation, health care, medical and dental consent, services and legal advocacy. The Guardianship Act 1987 has a set of overarching principles which guide decision making by both the Public Guardian and Guardianship Tribunal. The principles are aimed at promoting, wherever possible, the independence and choice, as well as ensuring the care and protection of the person under guardianship. They are:

- the welfare and interests of persons should be given paramount consideration
- the freedom of decision and freedom of action of the person should be restricted as little as possible
- the person should be encouraged as far as possible to live a normal life in the community
- the views of the person should be taken into consideration
- it is important to preserve family relationships and the cultural and linguistic environment of the person should be recognised
- the person should be encouraged as far as possible to be self reliant in matters relating to personal, domestic and financial affairs
- the person should be protected from abuse, neglect and exploitation
- the community should be encouraged to apply and promote these principles.
Executive Summary

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An investigation into new models of guardianship and the emerging practice of supported decision making.

Highlights:

- Exploration of the Mental Capacity Act in England with a diverse range of stakeholders.
- Discovering the principles of supported decision making in Canada and meeting people that had been bringing these principles to life for 10 years.
- Gaining knowledge from the experience of other jurisdictions in making significant legislative change in the areas of guardianship, decision making and adult protection.
- Learning how England and Canada have sought to answer the dilemma of enabling people's rights and autonomy while offering safeguards and protection.

Recommendations:

- Supported decision making should be facilitated by members of the community who are supporting people with disabilities in other areas of their lives.
- Supported decision making necessitates people with limited capacity having meaningful long term relationships outside of paid staff. Agencies that support people with limited capacity must be promoting opportunities for the development and maintenance of these relationships as part of a person centred approach.
- The Public Guardian could have a role in providing education to members of the community supporting people with limited capacity. Education would focus on the principles and values of supported decision making.
- That capacity assessment becomes decision specific in NSW for a person under guardianship.
- If this is not able to occur under the current legislation that consideration is given to changing the legislation to enable decision specific capacity assessment to occur. In doing so we would be making our guardianship practice least restrictive with regard to the legal rights of our clients.

Implementation and Dissemination:

Supported Decision Making Forum - 15 February 2011 (26 staff from the Public Guardian and 4 senior managers from Ageing Disability and Home Care)
Presentation at All Staff Day for the NSW Public Guardian - 15 March 2011.
Teleconference with the Standing Committee for the Supported Decision Making Trial in South Australia - 17 February 2011
Presentation of Fellowship Report to the Australian Guardianship and Administrative Council Members - 2011
Consultation with Ageing Disability and Home Joint Supported Decision Making Trial
Programme

25 October 2010 - 12 November 2010
London, England
Social Care Institute of Excellence — Mr David Thompson, Ms Alison Picton
Foundation for People with Learning Disabilities — Mr Toby Williamson, Ms Alison Giraud-Saunders
Department of Health — Mr Paul Gantley, Ms Lucy Bonnerjea
Cambridge House — Mr Martin Humes, Mr Martin Hampshire, Ms Charlene Verno
Advocacy Partners — Ms Amanda Peacock, Ms Sarah Welton
Norah Fry Research Centre — Ms Ruth Townsley, Mr Marcus Jepson, Ms Adele Lang, Ms Val Williams, Ms Kelley Johnson
Canterbury Christ Church University — Professor Hilary Brown
Tower Hamlets Local Area Authority — Ms Maggie McKinstry, Mr Peter Martin
Official Solicitor — Mr Robert Eckford
Office of the Public Guardian — Mr Martin John, Ms Joan Golbourn, Mr Jim Twist, Mr Keith Watts
Court of Protection — Senior Justice Denzil Lush, Ms Gaby Bradshaw
Mencap — Ms Beverley Dawkins, Ms Bella Travis
University of Cambridge — Professor Tony Holland, Mr Marcus Redley, Dr Isabel Clare, Ms Elizabeth Fistein.
Bournewood Case — Mr Graeme Enderby

15 - 18 November 2010
Toronto, Canada
Canadian Association for Community Living — Mr Michael Bach, Ms Anna MacQuarrie
Office of the Public Guardian — Ms Louise Stratford, Ms Laurie Redden
ARCH Disability Law Centre — Mr Ed Montigny
The Capacity Assessment Office — Ms Hilary Callin
Disability Lawyer and Consultant — Lana Kerzner
Deohaeko Family Support Network — Ms Helen Dionne, Mr Peter Dill
Disability Consultant — Mr John Lord

22 - 24 November 2010
Edmonton, Canada
Office of the Public Guardian — Ms Brenda Lee Doyle, Ms Shirley Peleshytyk, Ms Jody Wood, Ms Trish McOrmond, Ms Michelle Jasonson. Mr Rod Uriquito, Ms June King
Department of Health — Ms Moraika Purdon, Ms Helen Stokes, Ms Carol Anderson
University of Alberta Presentation — Mr Mark Handelman, Ms Tracey Bailey
Alberta Association for Community Living — Mr Bruce Uditsky, Ms Robin Acton
Office of the Public Trustee — Ms Cindy Bentz

29 - 30 November 2010
Calgary, Canada
Progressive Alternatives Society of Canada — Mr Stephen Wright

2 - 3 December 2010
Whitehorse, Yukon
Office of the Public Guardian and Trustee of Yukon Canada — Ms Judy Renwick
Social Care Services — Ms Jan Langford, Ms Nancy Kidd
Social Workers — Amy, Tom, Louise

6 - 16 December 2010
Vancouver, Canada
British Columbia Association for Community Living — Ms Faith Bodnar, Ms Layne Bryenton
Simun Fraser University — Dr Robert Gordon
NIDUS — Ms Joanne Taylor
BC Coalition of People with Disabilities — Ms Christine Gordon
The Public Guardian and Trustee of British Columbia — Mr Jay Chalke, Ms Kathleen Cunningham, Mr Raymond Leclair
Canadian Centre for Elder Law - Ms Laura Watts
Planned Lifetime Advocacy Network (PLAN) — Mr Al Etmanski, Ms Lauri Thompson, Mr Jack Styan, Mr Matthew Quetton
BC Centre for Elder Advocacy Support — Ms Joan Braun
Community Living British Columbia — Mr Brian Salisbury
Fraser Health Authority — Ms Leanne Lange
Vancouver Coastal Health — Ms Amanda Brown
London, England

Legislation

The Mental Capacity Act 2005, covering England and Wales, provides a statutory framework for people who lack capacity to make decisions for themselves or who have capacity and want to prepare for a future when they may not have capacity. It covers all types of decisions that are both small and large. The starting point of the legislation is that it is assumes an adult has full capacity to make their own decisions unless it can be shown that they lack capacity to make a decision for themselves at the time a decision needs to be made. It provides guidance on how to assess whether someone has the capacity to make a decision and when professionals should be involved in the assessment. The Act states that people must be given help and support to maximise their participation in the decision making process. If it is shown that an individual is not able to make their own decision someone else will become the decision maker. The substitute decision maker must make a decision in the best interest of the person. The legislation, and code of practice, outlines how to make a best interest decision on behalf of someone who lacks capacity at the time.

The legislation is guided by a set of five principles:

1) A person must be assumed to have capacity unless it is established they lack capacity.
2) A person is not to be treated as unable to make a decision unless all practicable steps to help them do so have been taken without success.
3) A person is not to be treated as unable to make a decision merely because they make an unwise decision.
4) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made in their best interest.
5) Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Additional to the Mental Capacity Act 2005 are the Deprivation of Liberty Safeguards (DOLS). The safeguards apply to people who have a mental disorder and lack capacity to consent to the arrangements of their care or treatment, but for whom receiving care or treatment in circumstances that amount to a deprivation of liberty may be necessary to protect them from harm and appears to be in their best interest. According to the DOLS Code of Practice in order to come within the scope of a deprivation of liberty authorisation a person must be detained in a hospital or care home, for the purpose of being given care or treatment in circumstances which amount to a deprivation of liberty. The Code of Practice lists a number of examples of cases where there has been a deprivation of liberty as determined by UK and European courts. They include the following: restraint is used, including sedation, to admit a person to an institution where that person is resisting admission; staff exercise complete and effective control over
the care and movement of a person for a significant period; staff exercise control over assessments, treatment, contacts and residence; a decision has been taken by an institution that the person will not be released into the care of others, or permitted to live elsewhere, unless the staff in the institution consider it appropriate; a request by carers for a person to be discharged into their care is refused; the person is unable to maintain social contacts because of restrictions placed on their access to other people; the person loses autonomy because they are under continuous supervision and control.

**Capacity Assessment**

The Mental Capacity Act offers an alternative framework to that found in NSW, for assessing capacity and the involvement of a substitute decision maker. Capacity is assessed by any person who is directly involved with the individual at the time the decision needs to be made. Capacity assessment is therefore not just in the realm of health professionals but also care workers, family members and service providers. The Code of Practice outlines a process that needs to be followed with regard to capacity assessment:

The starting assumption must always be that a person has the capacity to make a decision, unless it can be established that they lack capacity.

A person's capacity must be assessed specifically in terms of their capacity to make a particular decision at the time it needs to be made.

A person's capacity must not be judged simply on the basis of their age, appearance, condition or an aspect of their behaviour.

It is important to take all possible steps to try to help the person make a decision for themselves.

Assessing a person's capacity to make a decision should use the two stage test of capacity.

**Stage 1**

- Does the person have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works? (It doesn't matter whether the impairment or disturbance is temporary or permanent).

- If so does the impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made?

**Stage 2 (Assessing the ability to make a decision)**

- Does the person have a general understanding of what decision they need to make and why they need to make it?

- Does the person have a general understanding of the likely consequences of making, or not making, this decision?

- Is the person able to understand, retain, use and weigh up the information relevant to this decision?
- Can the person communicate their decision (by talking, using sign language or any other means)? Would the services of a professional (such as a speech and language therapist) be helpful?

Assessing Capacity to make more complex decisions
- Is there a need for a more thorough assessment (perhaps by involving a doctor or other professional expert)?

**Substitute Decision Making**

When it is assessed that the person lacks the capacity to be able to make the decision a best interest decision is made on behalf of the person. The Act suggests that many different people may be able to make decisions on behalf of a person. For most day to day decisions it will be the carer most directly involved. Where the decision involves the provision of medical treatment it will be the doctor or health care professional responsible for the carrying out the treatment who is the substitute decision maker.

For accommodation decisions in most cases it is the local authority who funds the accommodation place for the person that then needs to facilitate the decision making process, seek the views of stakeholders and make the final decision. If there is disagreement with the final decision the family or stakeholders can make a complaint to the local authority, the ombudsman and then finally to the Court of Protection (at a significant financial cost).

In the cases where there is no independent person such as a family member or friend who can advocate on behalf of the person who lacks capacity an Independent Mental Capacity Advocate (IMCA) becomes involved. IMCAs act in the place of the person who lacks capacity and are involved to ensure that the decision making process is fair and takes into consideration the needs of the person fully. IMCAs are not to provide a view regarding the correct decision and are not a decision maker.

In England it is very rare for a substitute decision maker to be appointed through the Court of Protection.

**The Court of Protection**

Under the Mental Capacity Act the Court of Protection is able to make specific decisions or appoint deputies to make decisions on behalf of people who lack capacity. It is a superior court with the same rights, privileges and authority as the High Court. The general powers of the court are to:

- Decide whether a person has the capacity to make a decision for themselves;
- To make declarations, decisions or orders on financial or welfare matters affecting people who lack capacity to make these decisions;
- Appoint a deputy to make ongoing decisions for people lacking capacity to make those decisions;
- Decide whether a Lasting Power of Attorney (LPA) or Enduring Power of Attorney (EPA) is valid;
- Remove deputies or attorneys who fail to carry out their duties; and
- Hear cases concerning objections to the registration of an LPA or EPA.

Through making its judgements the Court of Protection is developing a body of case law that will assist local authorities and other agencies to determine what is considered to be in the best interest of clients in complex situations.

A report published by the Court of Protection in 2009 stated that the majority of matters before the court relate to property and financial affairs. Very few applications made to the court are contested and in around 95% of cases an applicant does not need to attend a hearing.

This report goes on to clarify that there have been far fewer applications for personal welfare deputies than expected. The Mental Capacity Act and the supporting Code of Practice both emphasise that personal welfare applications should only be sought as a last resort. Section 50 of the Act requires the applicant to seek the permission of the court before making an application. The intention is to ensure that personal welfare applications are made in the best interest of the person. The Code of Practice states:

"...deputies for personal welfare decisions will only be required in the most difficult cases where:

- Important and necessary actions cannot be carried out without the court's authority, or
- There is no other way of settling the matter in the best interest of the person who lacks capacity to make personal welfare decisions," (p148)

The report also states that the court is refusing to give permission in up to 80% of personal welfare applications.

In England there is an Office of the Public Guardian, however its role is distinct from the NSW Public Guardian. In England the role primarily revolves around financial matters. The keys functions performed by the Office of The Public Guardian are to set up and manage a register for both Lasting and Enduring Powers of Attorney and a register for court orders that appoint Deputies. The office supervises Deputies and instructs court of protection visitors. The office also receives reports from Deputies and Attorneys acting under the LPAs. The office also provides the court of protection with reports as requested when concerns have been raised about an Attorney or Deputy.

The Office of the Public Guardian is not a substitute decision maker for either financial or personal welfare decisions. In England there is no independent, statutory body who can act as deputy of last resort.

**Supported Decision Making**

One of the principals of the Mental Capacity Act states that all practicable steps are to be taken to assist the person to make a decision before determining they are unable to
make the decision. The assistance offered to the person is in essence supported decision making. Below is a summary from the Code of Practice which outlines key areas to be considered when assisting someone to make a decision:

Providing relevant information

- Does the person have all the relevant information they need to make a decision?
- If they have a choice, have they been given information on all the alternatives?

Communicating in an appropriate way

- Could information be explained or presented in a way that is easier for the person to understand (for example, by using simple language or visual aids)?
- Have different methods of communication been explored if required, including non-verbal communication?
- Could anyone else help with communication (for example, a family member, support worker, interpreter, speech and language therapist or advocate)?

Making the person feel at ease

- Are there particular times of day when the person's understanding is better?
- Are there particular locations where they may feel more at ease?
- Could the decision be put off to see whether the person can make the decision at a later time when circumstances are right for them?

Supporting the person

- Can anyone else help or support the person to make choices or express a view?
- Where possible, choose a location where the person feels most at ease.

Reflections

The Mental Capacity Act has been ambitious in its attempt to generalise responsibility of capacity assessment to the wider community. It is attempting to create a complete cultural shift which moves away from the assumption that disability equals incapacity and moves towards the assumption of capacity for all adults unless proven otherwise. The development of the legislation recognised there was a need to provide principles and guidance to ensure all people knew how to fairly assess a person's capacity.

Social Care staff from the local authority in Tower Hamlets spoke of a change in focus that had occurred since the introduction of the legislation. They now must assume a person has capacity and support them to take risks, or make an unwise decision, if they are assessed to have capacity. Staff believed this had led to better outcomes for clients with the focus shifting from protection to whether an individual has the capacity to assess the risk themselves. When someone is found to lack capacity they now have a clear framework within which to make a best interest decision. This process was much more ambiguous previously. The local authority must now involve family and key stakeholders in the decision making process.
In reality this doesn't always occur, however there was no obligation to involve family previously and most parties suggest the current situation is better for all parties, including the adult, as a result.

The principles outlined in the legislation are very much in line with those discussed at the United Nations Convention of the Rights of Persons with Disabilities. The Convention was negotiated over eight sessions in the general assembly of the United Nations between 2002 and 2006 and created a paradigm shift in attitudes and approaches to people with disabilities. It has attempted to shift the view of people with disabilities from being objects of charity, treatment and protection to people with rights who are capable of determining their own lives.

The Mental Capacity Act, particularly in relation to capacity assessment, is more successful than other Acts in ensuring people's legal decision making rights are restricted as little as possible. It does so by assessing capacity for each and every decision rather than making a blanket assessment of incapacity for a period of time. As such the legislation better addresses the needs of a person with fluctuating capacity eg. people with mental illness.

In NSW our Guardianship Act enables a substitute decision making Order to be made with specific areas of authority over a determined period of time. Although individual guardians seek the view of the person under guardianship for each decision that needs to be made, upholding someone's view and being the legal decision maker are different. I believe more could be done in NSW to ensure people's legal decision making rights are upheld. It could be determined if there is scope within the legislation to enable an assessment of capacity each time a decision is required for a person under guardianship. This is possible under Part 5 of the Guardianship Act which addresses medical treatment. This is discussed in more detail in my recommendations.

If a new perspective on capacity assessment is the greatest strength of the Mental Capacity Act then the greatest weakness would have to be the absence of an independent substitute decision maker. The best interest process outlined in the Code of Practice has the potential to be significantly undermined by a conflict of interest for the decision maker and possibly the independent advocates set up to protect the interests of vulnerable people without support.

From my discussions with a number of stakeholders I am concerned about two potential conflicts of interest. The first is that the professional who is making the best interest decision has a vested interest in the outcome of the decision. For example, the doctor who proposes a medical procedure is also the person who decides if the procedure is in the best interest of the person. If the stakeholders involved in the best interest decision making process are not empowered to challenge the treating doctor this may lead to decisions not being made in the person's best interest but instead being dictated by a range of competing interests. Family groups and carers expressed frustration that they were in a reactive position which was relatively powerless. The process of challenging decisions was often laborious, required courage and knowledge of government systems which many families did not have.
The second concern regarding conflict of interest relates to IMCA services. The role of an IMCA service is to provide independent safeguards for people who have no one else to support or represent them in the decision making process. IMCA services are to be independent however they are funded by the local authorities who are often substitute decision makers. It is reasonable to question the ability of IMCA services to remain independent when local authorities may find being challenged difficult. It would seem inevitable that IMCA services will be pressured by those who fund them, not to take matters further, for example to the Ombudsman or Court of Protection. Department of Health disagreed with these concerns however IMCA services confirmed that on the first occasion they took a local authority to the Court of Protection their contract was threatened. It was clear from my meetings with IMCA services that they were committed to the important work of protecting the most vulnerable and that they had no intention of compromising their service to clients as a result of pressure. It will be interesting to learn whether these potential conflicts of interest manifest themselves in the coming years when the pressure on resources increases as the financial situation in the United Kingdom becomes more serious.

Another area of interest to all working with people who lack capacity is the tension that exists between rights and protection. The Code of Practice states:

"The Act aims to balance an individual's right to make decisions for themselves with their right to be protected from harm if they lack capacity to make decisions to protect themselves." (pg 15)

Professor Hilary Brown from Canterbury Christ Church University raised concern that there appears to be some ambiguity regarding who becomes the decision maker in complex matters. In reviewing a number of complex case histories she noted that this lack of clarity frequently resulted in a lack of action being taken to protect vulnerable adults. Professor Brown is involved in the development of additional guidelines which will work alongside the Code of Practice to offer direction to service providers and agencies for more complex decision making. This insight was not only expressed by Professor Brown.

A round table discussion at Cambridge University also touched upon similar concerns that the Mental Capacity Act may not have given adequate consideration to the obligation to protect vulnerable people from abuse, neglect and exploitation. The focus has been squarely on autonomy for some time and perhaps the tide is changing enabling greater recognition that there are some people who as a result of a variety of factors (internal and external) are intrinsically vulnerable. During a presentation of the principals that underpin the Guardianship Act in NSW the team at Cambridge reflected that our practice of weighing guardianship principles against one another when making a best interest decision was beneficial. This consideration of the competing values of autonomy and protection in the decision making process is not explored thoroughly in the Mental Capacity Act nor the Code of Practice.

I was interested to explore whether the addition of the Deprivation of Liberty Safeguards (DOLS) redressed in some way the balance with regard to protecting vulnerable adults. Individuals working within local authorities reported that the definition of what
constitutes a deprivation of liberty sets a high bar. Their experience was that very few applications for authorisations had been made in their local area. They proposed this was because the legislation defines a deprivation of liberty as a restriction that has a level of frequency, intensity and duration that is beyond any practices being used in their group homes and care facilities. Given this is the case they were not of the view that DOLS assisted in balancing the rights of individuals with the obligation to protect vulnerable adults.

In concluding my reflections on exploring the Mental Capacity Act I would suggest we are very fortunate in NSW to have the Public Guardian, a statutory body, that can make decisions independently on behalf of our clients. An independent statutory body has no vested interest in the outcome of the decisions made on behalf of clients. This independence enables stronger advocacy for clients and non-partisan best interest decision making to occur. There is a wealth of knowledge and experience which accumulates over time within such an office. Best practice guidelines can be developed and precedence set with regard to complex decision making.

Guardianship practice in Australia would benefit considerably from embracing the value England places upon the rights of individuals to be autonomous and not be labelled as a person who lacks capacity. A commitment to assessing a person's capacity to make each and every decision means that a person's legal decision making rights truly are restricted to the least extent possible. I believe there is more that could be done to bring our own guardianship practices in line with the direction England has taken in the Mental Capacity Act. There is tremendous value in reframing our assumptions regarding capacity assessment and having legislation that enables assessment of capacity to be made for every decision necessary.
Legislation

There are two pieces of legislation that together create options for people who are deemed incapable of making their own decisions in Ontario, Canada. The Substitute Decisions Act which came into force on 3 April 1995 and the Health Care Consent Act on 29 March 1996.

The Substitute Decisions Act uses language consistent with the model of disability held at the time the legislation was created. It describes how a decision maker is appointed for a "mentally incapable person" and there are different procedures to follow depending on whether the decisions to be made relate to property and finances or health and housing.

There are three ways for a substitute decision maker to be appointed for a person who is incapable of making property decisions: by creating a continuing power of attorney prior to the person losing capacity, through assessment of capacity resulting in statutory guardianship or through the appointment of a guardian by the court. There are two ways for a person to have a substitute decision maker appointed for personal decisions: through creating a power of attorney for personal care which must be created prior to the person losing capacity or through the appointment of a guardian by the court.

The Health Care Consent Act covers decisions about treatment, admission to long-term care facilities and personal assistance services to people in those facilities. The Act outlines a hierarchy of substitute decision makers to provide consent to medical treatment similar to that found in the Guardianship Act in NSW. It is as follows:

1. A guardian appointed by the court if the court order authorises the guardian to make health care decisions
2. A person with a power of attorney for personal care authorising him or her to make health care decisions
3. A representative appointed by the Consent and Capacity Board (any person may apply to the board to be appointed as the substitute decision maker)
4. A spouse or partner
5. A child or parent (custodial parent if the child is a minor)
6. A parent who has access rights (if the patient is a minor)
7. A brother or sister
8. Any other relative
9. The Office of the Public Guardian and Trustee

Protections are built into the Health Care Consent Act to ensure the person is given the opportunity to challenge the finding that he or she is incapable which includes having the opinion reviewed by the Consent and Capacity Board.

The Health Care Consent Act established the Consent and Capacity Board as an
independent provincial tribunal to adjudicate consent and capacity issues. The key activities of the Board are matters of capacity, consent, civil committal and substitute decision making. Over 80 percent of applications to the Board involve a review of a person's involuntary status under the Mental Health Act, or a review under the Health Care Consent Act of a person's capacity to consent to or refuse treatment.

**Guardianship**

Statutory guardianship in Ontario means that a guardian is appointed to manage the property of a person who is deemed to lack capacity without going to court. There are two ways in which this can occur. The first is if a person is admitted to a psychiatric facility under the Mental Health Act. All patients of psychiatric facilities are assessed to determine if they are incapable of managing their property. The Mental Health Act outlines the process for issuing a Certificate of Incapacity which automatically results in the Public Guardian and Trustee becoming the statutory guardian. Patients have a right to appeal the assessment of incapacity and request a review by the Consent and Capacity Board. Prior to the Substitute Decisions Act coming into force outpatients of psychiatric facilities and also residents of facilities for people with developmental disabilities were also subject to this practice.

The second process is identical in that someone from the community can come under statutory guardianship is if they are assessed as incapable of managing property and an independent assessor issues a Certificate of Incapacity to the Public Guardian and Trustee.

The Substitute Decisions Act specifies that the process of issuing a Certificate of Incapacity must be followed to ensure a person is informed of what is happening and that they are aware of their rights. An assessment for statutory guardianship cannot be performed until the assessor explains to the person its purpose, the effect of the finding about the person's capacity and the person's right to refuse to be assessed. When an assessor issues a Certificate of Incapacity to the Public Guardian and Trustee they must ensure the person is informed in an appropriate manner that the Public Guardian and Trustee has become the person's statutory guardian, and that the person is entitled to apply to the Consent and Capacity Board for a review of the assessor's finding that the person is incapable of managing property.

There is a process in the Act that allows an incapable person's attorney, spouse, partner, relative or in certain circumstances trust corporations to apply to take over statutory guardianship from the Public Guardian and Trustee.

Court ordered guardianship occurs in certain circumstances such as when a person is believed to be incapable and in need of guardianship but refuses to be assessed, when an applicant wishes to take over after the Public Guardian and Trustee has become statutory guardian and is not the person's attorney and is also not their spouse, partner, relative or a trust corporation and when there are grounds to believe there has been mismanagement by the attorney or the statutory guardian.

The court must determine that the individual is incapable of managing their property, that
the incapable person needs to have decisions made about their property and there is no less restrictive course of action that could be pursued which would address the need for making decisions. The court will also determine the suitability of the proposed guardian and their management plan.

The court is also able to appoint a guardian for the person to make decisions with respect to personal care rather than financial and property matters. An order can be for full guardianship covering all aspects including health care, food, housing, clothing, hygiene and safety. If this person is capable in some areas the court may make a partial guardianship order covering only the areas in which the person is incapable.

The Office of the Public Guardian and Trustee has a number of functions including appointing private individuals as statutory guardians for property, investigating reports of serious abuse or neglect of incapable persons, acting as a last resort decision maker for medical treatment, keeping a register of guardians for property and personal care, and acting as guardian of last resort.

**Supported Decision Making**

Family members and carers of people with disabilities in Toronto offered some unique personal experiences of supported decision making. For them supported decision making had been occurring in Ontario through the use of circles of support for over twenty years. Family members shared that these experiences had been largely positive however not without its challenges.

Circles of support are a group of approximately five to ten people that meet to discuss the goals and dreams of a person's life. It can be very structured or very informal depending upon the wishes of the person. Groups can meet on a regular or as needs basis. Supporters primarily listen to the person and support them to make decisions and take steps necessary to achieve their goals. Ms Helen Dionne from the Deohaeko Family Support Network shared that a circle of support is meant to offer a circular approach to ideas and resolving issues. A dialogue occurs which is guided by the individual who needs support. It cannot be a linear process that is focused on a particular outcome. Mr Peter Dill from the same organisation expressed concern that if supported decision making were legislated it would inevitably become linear as a result of requiring certain outcomes from the process. At its very heart supported decision making is about making the person with a disability the driver of any process. If the person starts to come secondary to achieving certain outcomes, such as making decisions that other people feel are important, then it ceased to be supported decision making. The process has changed from being circular to linear.

Mr John Lord, disability consultant, spoke about three essential aspects of supported decision making: principles, people and process. The principles must underpin everything. Having the right people involved to offer support is essential and the process determines how the principles work in practice. Mr Lord was of the opinion that there are many processes that can work to achieve the principles of supported decision making. For some people a representation agreement might be best for others in
might be a circle of support. Mr Lord reflected that without a clear foundation with regard to the principles a community would not be able to develop processes that enable supported decision making. Debate and education of the principles had occurred in Ontario over a period of twenty years.

**Reflections**

The Office of the Public Guardian and Trustee in Toronto focuses principally on financial and property management rather than substitute decision making for personal care matters. The Office has a role in providing one off substitute consent to medical treatment for people who lack capacity to give medical consent and do not have anyone else who could act as person responsible. These legal provisions offer people a less restrictive alternative to clients than a guardianship order. In NSW although treating medical practitioners assess a person's capacity to give valid medical consent each time treatment is needed when a guardianship order is in place people are stigmatised with the label of being under guardianship. The Guardianship Act in NSW does allow the Guardianship Tribunal to provide one off consent to medical treatment. I believe it would be of benefit to explore what resources would be required to enable the Guardianship Tribunal to provide one off consent to medical treatment consistently rather than just in exceptional circumstances.

The specific wording of the Health Care Consent Act gives people the ability to make substitute decisions on behalf of people lacking capacity to enter long term care facilities. Unfortunately the wording of the legislation excludes the ability to consent to an accommodation placement in a group home or retirement home. It is of concern that by narrowing the scope of the Act it may place vulnerable people risk. Without any independent involvement and advocacy on behalf of the incapable person there is a risk that decisions regarding long term accommodation may not be made in the best interest of the person.

Another concern in relation to people not having an adequate voice would be in relation to the automatic appointment of the Public Guardian and Trustee when someone is found to lack capacity to manage their finances and property. It would seem unfair that the person who is said to lack capacity does not have any right to object to the appointment of the Public Guardian and Trustee prior to it being implemented. There is a significant difference between being determined to lack capacity and it being reviewed from having the opportunity to object to the implementation of the regime prior to it coming into effect. This system seems to lack procedural fairness and does not give people the opportunity to express a view in a forum that may alter the outcome. Similarly it is of concern that people are not able to nominate a preferred guardian such as a family rather than having a statutory body appointed. The statistic discussed was that family members apply to take over as guardian in less than 10 percent of cases.

The Canadian Association for Community Living raised a number of concerns in relation to the unfairness of current systems of guardianship not only in Ontario and Canada but all over the world. They disagreed with schemas that labelled people as incapable and that did not recognise people with disabilities are able to be supported to make significant
life decisions themselves. A round table discussion held with a number of people from legal, academic, and disability service backgrounds discussed the challenges of defining capacity and thresholds which are meaningful. There was consensus that it would be of benefit to legislate supported decision making because despite these models being used informally for some time it was believed that supporters would never be appropriately recognised until they had legal standing. It was not clear from the discussion what a best practice model of supported decision making would look like though there seemed to be some agreement that the Representation Agreement in British Columbia offered people a better alternative to statutory guardianship. The representation agreement seemed to promote the values articulated in the United Nations Charter on the Rights of Persons with Disabilities more closely than any other in Canada at this time.

The Public Guardian and Trustee recognised that there was increasing community pressure to review the Substitute Decisions Act and that it was becoming out of step with current thinking in the disability community. However they expressed concern that the models of supported decision making with which they were familiar appeared to lack structured safeguards to protect vulnerable people. They had concerns that without appropriate safeguards in place supported decision making agreements would leave people exposed to exploitation.

Another interesting idea discussed at the meeting with the Canadian Association for Community Living was that most guardianship legislation takes into account or is shaped by extreme scenarios (eg people who are in a coma or vegetative state). The thesis was that this focus on extreme scenarios has led to legislation not reflecting the needs of people with less significant conditions. It is these individuals who would benefit from supported decision making. My opinion is that good legislation must take into consideration people with varying degrees of capacity. Whether separate legislation is required to do justice to both I am unsure. However legislation that only accounts for one group of individuals will be either overly restrictive or lacking adequate safeguards.
Edmonton and Calgary, Canada

Legislation

On 30 October 2009 Alberta introduced new legislation which replaced the Dependent Adults Act which was thirty years old. The Adult Guardianship and Trusteeship Act aimed to provide more options and safeguards to protect vulnerable adults who are unable to make personal or financial decisions independently. It offers a range of decision making options such as supported decision making authorisations, co-decision making court orders, full guardianship and trusteeship.

The Adult Guardianship and Trusteeship Act is based on a set of guiding principles which are as follows:

1. An adult is presumed to have the capacity to make decisions until the contrary is determined.
2. An adult is entitled to communicate by any means that enables the adult to be understood, and the means by which an adult communicates is not relevant to a determination of the adult's capacity.
3. An adult's autonomy must be preserved by ensuring that the least restrictive and least intrusive form of assisted or substitute decision-making that is likely to be effective is provided.
4. In determining whether a decision is in an adult's best interests, consideration must be given to any wishes expressed by the adult while capable and any values and beliefs known to have been held by the adult while the adult had capacity.

![Decision-making Continuum Diagram]
Guardianship

The Office of the Public Guardian was responsible for developing and drafting the new decision making legislation in Alberta. Ms Brenda Lee Doyle, Public Guardian, articulated a clear vision and direction for the legislation that is to offer people with limited capacity in Alberta more options and greater control over their lives.

The key to this vision was to create a decision making continuum which runs along side a continuum of capacity. This vision was brought to life with regard to personal and welfare decision making. The diagram on the previous page shows clearly the options created for people as they move from being a person with full capacity to someone who lacks long term capacity. It was interesting to note that with regard to a person's financial matters the legislation in Alberta has not created options for people other than full trusteeship. Ms Cindy Bentz, the Public Trustee in Alberta, reflected that despite attempts to create innovative options for people with limited capacity they were unsuccessful. The Public Trustee has some informal mechanisms of supporting people within the community (eg direct debt arrangements) however there are not any equivalent options to representation agreements or co-decision making agreements. This will be discussed in more details in my recommendations.

Supported Decision Making

The first option along the continuum is for an adult who has the capacity to make their own decisions but who would like some help. In this situation the adult can sign a form that authorises someone they trust to be their "supporter". The adult can give their supporter legal permission to access relevant information that might otherwise be protected under privacy laws. The supporter is able to help the adult think through the decision making process and communicate decisions, if necessary. Guidelines set out by the Office suggest a supported decision making authorization would be helpful for capable individuals who face complex personal decisions, people whose first language is not English and people with mild disabilities.

Co-Decision Making

The second option is for an adult whose ability to make decisions is significantly impaired however they can make their own decisions with good support. A co-decision making order is seen as an alternative to guardianship in these situations. With a co-decision making order, the adult and their co-decision maker make decisions together. The adult must agree to the arrangement, as well as the person who is appointed by the Court as their co-decision maker. A capacity assessment must be done and submitted to Court with the application. The Capacity Assessment Report enables the court to determine whether a co-decision making order is the best option for the adult. A co-decision maker is accountable to the Court for the decisions made with the assisted adult. Anyone is able to request a review by the Court of the co-decision making order at anytime. The Office recommends that a co-decision making order would be appropriate for family and close friends.
Specific Decision Making

When an adult is assessed by a health professional as being unable to make a health care decision, and they do not have a guardian or personal directive, the health professional may choose the nearest relative to act as a specific decision maker to make the decision. Decisions are restricted to specific areas: health care treatment or temporary admission to or discharge from a residential facility. When there is no relative, or there is conflict, the Office of the Public Guardian is able to make the decision.

Guardianship

If an adult is assessed to lack the capacity to make personal decisions, the Court may appoint a guardian to make personal decisions for them. A guardian can make personal decisions for the adult in a number of areas depending on the adult’s needs. They may include health care, where the adult is to live, with whom the adult may associate, social activities, education, employment and legal matters. It is usually a family member or friend that applies for guardianship, but if no one is willing or available the Office of the Public Guardian can act as the guardian of last resort.

The Office of the Public Guardian in Alberta performs a similar role to the Public Guardian in NSW. It has an additional investigative role that prior to the appointment of any guardian they will investigate the appropriateness of the application and provide a view to the Court. The Office also has a role in investigating complaints made about the welfare of people under guardianship or co-decision making orders.

Supported Decision Making

From discussions with a number of community stakeholders it would seem it is too early to determine whether the supported decision making options for people in Alberta are being utilised. There is no register of supported decision making authorizations and as a result it will be difficult to determine in the future the prevalence and success of this tool.

Consultation with the Alberta Association for Community Living and the Department of Health suggested that people are not really utilising these tools yet. Family members, and carers, of people who have limited capacity suggested that they will not be exploring supported decision making authorizations until they have a need. They suggested the only circumstance in which they could foresee such a need was interacting with health professionals who would not accept their role as an informal supporter. The supported decision making authorizations are not valid in relation to financial matters and family members suggested that this was perhaps the area where it would have been most useful.

It was interesting to discuss with the Office of the Public Guardian why they perceived there was a need to legislate supported decision making. The primary motivation was an ideological position that sought to have the change in community definitions of capacity defined in legislation. There was also a pragmatic need to resolve a significant issue for health professionals regarding access to private information for supporters of people with disabilities.
Though information on the use of supported decision making authorizations is limited statistics regarding co-decision making orders are more accessible. At the time of my visit in November 2010 there had been ten co-decision making orders made by the Court over a twelve month period. There were another thirty that were in the application process. It will be of interest to track over time whether an increase in co-decision making orders has an impact on the number of guardianship orders made in Alberta.

Reflections

It has been interesting to reflect on how involved the Office of the Public Guardian was in the process of the legislation changing in Alberta. They facilitated the community consultation process, drafted the legislation and have been responsible for its implementation.

Mr Peter Lown, Executive Director of the Alberta Law Reform Commission, spoke of the importance of cultural change and a clearly defined need for such a change to precipitate any law reform process. Mr Lawn believed it was essential that one agency is responsible for championing this need for change and outlining the policy that is required to get to the end goal. Mr Lown supported the proposal outlined in the NSW Legislative Council Enquiry that any new guardianship legislation in NSW be moved under the auspices of the Department of Justice and Attorney General. This would enable the Public Guardian to have a greater sense of ownership over the legislation in the future which would be necessary to oversee any significant legislative change. The Mental Capacity Act did not have one government agency which was responsible for overseeing its implementation. A question asked by many people in England was after the three year implementation period ceases who will agencies turn to for support, guidance and assistance in resolving ongoing issues with the legislation? The thoughts of Mr Lown, and experiences in both Alberta and England, highlight the importance of planning for the long term implementation of new legislation.

Ms Brenda Lee Doyle spoke of the significant amount of time and energy that had been invested in consulting with community stakeholders to seek their views and educate them with regard to the need for cultural change. In Alberta the most complex and challenging stakeholders to engage in the change process were the legal and health communities. This was consistent with the experience of others responsible for overseeing the legislative change in England. These groups obviously have specific areas of expertise and require specialised information and support to understand how legislative changes will affect their practice. It is noted here so that consideration is given as to how to engage these two groups of stakeholders if NSW changes its legislation.

It would appear that the collaborative approach taken by the Office of the Public Guardian has been significant factor in enabling the successful introduction of the legislation. The implementation of the legislation has not been without its challenges however by in large stakeholders were willing to work together to resolve such problems because there was universal commitment to the principles which underpin the legislation and the reason for change.
It will be interesting to follow the implementation of the Adult Guardianship and Trusteeship Act over the coming years. There will be much interest, across not only Australia but internationally, in whether the continuum of decision making options results in any decrease in the need for full guardianship for people with limited capacity in Alberta.
Yukon, Canada

Legislation

Yukon, Canada has a suite of Acts that combine to provide support to people with varying degrees of capacity. They are known as the Decision Making, Support and Protection to Adults Act which was assented to 17 November 2003. The key Acts of interest to my investigation were the Adult Protection and Decision Making Act, the Care and Consent Act and the Public Guardian and Trustee Act.

The Adult Protection and Decision Making Act was enacted on 2 May 2005 in Yukon, Canada. It includes provision for supported decision making agreements, representation agreements, court appointed guardians and a mandate for designated agencies to offer assistance to adults who are abused and neglected and unable to seek on their own behalf.

The Care Consent Act applies to both adults and children and it covers how medical and health professionals obtain and seek substitute consent for medical treatment. Care providers assess whether a person is capable of providing their own consent or whether a substitute decision maker is required. There is a hierarchy of person responsible similar to that in NSW. The substitute decision maker of last resort in Yukon is the consent of two or three health care providers. The Care Consent Act also established the Capability and Consent Board which reviews the determination of incapacity if there is dispute. The Act also makes provision for advanced directives whereby a person nominates a proxy to make care decisions on their behalf should they lose capacity. Finally the Act offers temporary financial protection for someone who is rendered incapable in the short term as a result of ill health. The Public Guardian and Trustee can manage a person's finances for up to 60 days under these provisions.

The Public Guardian and Trustee Act established the office of the Public Guardian and Trustee which continued its role as a public administrator while accepting the additional responsibility of guardian of last resort, investigator of financial abuse, temporary estate protection and involvement in private guardianship applications.

Guardianship

Guardianship is court appointed in Yukon. The court process is both formal and expensive. The Office of the Public Guardian and Trustee reviews applications being submitted to court that are recommending the involvement of their Office. Guardianship orders are for specific domains in a person's life however once in place are not reviewed unless the matter is taken back to court. Guardianship applications rely upon capacity assessment forms which are completed by health professionals.

Capacity assessment for court hearings has been a problem in Whitehorse where there is limited access to Specialists. Health professionals are reluctant to take on the responsibility of assessing someone's capacity knowing that the assessment report will be the basis of someone losing their independence and decision making rights in the long term. There is a significant fee charged by health professional to
assess a person’s capacity for Court in the vicinity of $2000 - $3000. The cost of arranging a capacity assessment, and the subsequent cost of taking a matter to Court, is a barrier to families applying to be legal guardian of a relative. As a result the Public Trustee and Guardian reported there are very few people under guardianship in Yukon.

Guide to Using Yukon Decision-Making Tools

There are a number of tools set out in Yukon legislation to assist people who may need help making decisions (e.g. financial, health care, personal care, legal, etc.). Deciding which tool is best for the individual is not always straight-forward. This guide is meant to assist health and social service professionals to find the most suitable decision-making tool.

<table>
<thead>
<tr>
<th>TOOL</th>
<th>LEGISLATION</th>
<th>KEY INFORMATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance Directive</td>
<td>Care Consent Act, Part 2</td>
<td>Prepared in advance while person still capable. Individual can name a substitute decision-maker (“proxy”) and set out their wishes for health care and personal care.</td>
</tr>
<tr>
<td>Supported Decision-Making Agreement</td>
<td>Adult Protection and Decision-Making Act, Part 1</td>
<td>Agreement between two adults formalizes support arrangements. Adult must be capable of understanding nature and effect of agreement.</td>
</tr>
<tr>
<td>Representation Agreement</td>
<td>Adult Protection and Decision-Making Act, Part 2</td>
<td>Agreement between two adults authorizes a “representative” to make limited day-to-day financial decisions. Adult must be capable of understanding nature and effect of agreement.</td>
</tr>
<tr>
<td>Adult Protection</td>
<td>Adult Protection and Decision-Making Act, Part 4</td>
<td>Adult Protection (HSS) can refer a suspected case of financial abuse to Public Guardian and Trustee (PGT) who can then freeze/control the adult’s accounts while they investigate (21 days).</td>
</tr>
<tr>
<td>Certificate of Need for Financial Protection (sometimes referred to as “statutory guardianship”)</td>
<td>Care Consent Act</td>
<td>Person must be incapable of making a care decision and also unable to manage their finances. Certificate filled out by health care provider, sent to (PGT) who can then manage the person’s finances for up to 60 days.</td>
</tr>
<tr>
<td>Temporary Guardianship</td>
<td>Adult Protection and Decision-Making Act, Part 3</td>
<td>Compelling evidence to indicate that person needs finances managed. Application to Supreme Ct does not require incapability assessment, but does require letter from health care provider. Court can grant guardian for finances for up to 180 days.</td>
</tr>
<tr>
<td>Guardianship</td>
<td>Adult Protection and Decision-Making Act, Part 3</td>
<td>Upon application by family or PGT, Supreme Court of Yukon can appoint a guardian in one or more decision-making domains.</td>
</tr>
</tbody>
</table>

For more information, see www.hss.gov.yk.ca (Care Consent Act, Adult Protection, Advance Directives, Practice Guidelines for Incapability Assessments); and www.publicguardianandtrustee.gov.yk.ca (Guardianship)

Supported Decision Making

The legislative framework in Yukon offers a continuum of options for people including advanced directives, supported decision making agreements and representation agreements. In a meeting with staff from Social Care Services in Yukon it was expressed that the primary reason supported decision making agreements were created was in response to requests from community disability and advocacy groups.
It was identified that changing views of people with disabilities required a change in legislation to make a clear political and ideological statement. From a policy perspective there was limited perceived benefit to legislating what had been working informally. However the dialogue with community organisations identified there was strong community support and the government could see no real harm in formalising these arrangements.

During preliminary legislative discussions there had been a recommendation to register the supported decision making agreements however there were not the financial resources to establish such a registry. It was acknowledged by stakeholders across Canada that a registry would allow some oversight of agreements however with the exception of British Columbia none of the provinces visited had a registry.

Supported decision making agreements are voluntary in Yukon. A person, and their supporter sign the supported decision making agreement form that it witnessed by a third independent person. In contrast to the supported decision making authorization in Alberta an agreement does not allow the supporter, or associate, to have access to personal information. The associate is still required to obtain the consent of the adult to access their private information. The thinking behind this was that if a person doesn't require a substitute decision maker then they could still provide consent to a release of their information. The associate can assist the adult to obtain information. The focus of the arrangement is assisting the individual. The associate doesn't have any power over the individual. The presence of an agreement means there is a duty for people to consult with the associate when significant decisions are being made by the individual. There is some case law in Yukon that suggests if the associate is not consulted when a significant decision is made the decision may be reversed (eg the purchase of a new car could be terminated) as the person may have made a different decision with the support of their associate. The legislation also clarifies that the associate is not liable if the person makes an unwise decision against the advice of their associate.

A representation agreement in Yukon is also a private arrangement between two individuals however there is a level of accountability when created. When a representation agreement is signed it must be witnessed by a Social Worker who is trained to check for any sign of coercion involved in the establishment of the agreement. The Social Worker will check what the obligations and responsibilities are set out within the agreement. Despite having to be witnessed by the Social Worker the agreement is not registered anywhere.

The focus of a representation agreement is to assist someone with their day to day financial matters. It targets a population of people who are relatively independent but don't have money management skills. There are limits on the kind of financial decisions that are able to be made under a representation agreement. Though the rationale for the establishment of the representation agreements is sound the reality is that there are very few agreements in place in Yukon. Social Workers suggested this was because most people in need of the agreements didn't have someone in their life who could offer them the informal support they required. It was suggested that even without representation
agreements there are a number of other tools that are assisting people to continue managing their own finances eg direct debit of bills.

Reflections

Although supported decision making agreements and representation agreements have existed in Yukon for over five years it appears there has been limited use of these tools. Stakeholders suggested this is primarily because the people who would benefit from these agreements do not have close trusting relationships with people capable of being a representative or associate. This issue was of concern in a number of jurisdictions but was demonstrated most starkly in the remote environment of Whitehorse, Yukon.

This reality highlights the need for meaningful inclusion for people with disabilities. Opportunities for people to build significant, long term relationships with individuals other than paid carers are essential for a good quality of life. The introduction of supported decision making relies upon the assumption that people with limited capacity have such relationships in their lives.

As jurisdictions in Australia seek to trial supported decision making it will be critical to assess the extent to which people are included in social networks outside of paid carers. It may be that efforts need to be made to promote integration and meaningful inclusion prior to the implementation of supported decision making tools. The success of the implementation of these options will rely upon these relationships being in place. I believe it is essential to recognise the interconnectedness of inclusion and supported decision making before progressing with the implementation of these new tools.
Vancouver, Canada

Legislation

British Columbia has four laws which are designed to promote the self determination, support and protection of people who are no longer capable of making their own decisions. The four Acts that together comprise guardianship legislation in British Columbia are:

1. The Representation Agreement Act
2. The Health Care (Consent) and Care Facility (Admission) Act
3. The Adult Guardianship Act
4. The Public Guardian and Trustee Act

On 28 February 2000 some of the legislation was enacted however other parts of the legislation are still to come into effect. The Public Guardian and Trustee of British Columbia website clarifies that the following parts of the legislation came into effect.

Representation Agreements — The Act is set up to address the needs of a person should they become incapable of making their own decisions. Representation agreements can cover all aspects of an adult's life — health and personal care, as well as financial and legal matters.

Support and Assistance for Adults who are Abused or Neglected — Part 3 of the Adult Guardianship Act promotes a co-ordinated community response to abuse, neglect or self-neglect. The Act emphasises the importance of support and assistance and provides new tools for intervening when abused or neglected adults are found to be incapable of making the decision to refuse assistance.

Health Care Consent Law — The consent provisions affirm the right of adults to make their own health care decisions and to have those decisions respected. When an adult is incapable of giving consent, procedures are set out that allow family members to give substitute consent. The Public Guardian and Trustee will act as decision maker when there is on one else to assist.

Public Guardian and Trustee Act — This Act clarifies the powers of the Public Guardian and Trustee in the investigation of financial abuse. It changes the name "Public Trustee" to "Public Guardian and Trustee" and provides for more accountability in service planning and performance reporting.

There were two important pieces of legislation that were not brought into force. The first was the Adult Guardianship Act — Part 2. This part of the Act was intended to replace the Patients Property Act by providing a revised system of formal court appointments for substitute decision makers where necessary. The Patients Property Act was reported to be outdated and no longer in line with the current thinking regarding the rights of people with disabilities. The second was the Care Facility (Admission) Legislation. This part of the Health Care Consent and Care Facility Admission Act sets out procedures for the admission of adults to care facilities.
Disability organisations in British Columbia expressed that the development of the four Acts had the intention of limiting the role of guardianship to the greatest possible extent. This intention had been frustrated by not all of the legislation being enacted at the same time. The Public Guardian, Mr Jay Chalke, suggested ongoing attempts were being made by the Public Guardian and Trustee to make further legislative change a political priority for government.

Dr Robert Gordon, Professor of Criminology at Simon Fraser University, who was involved in the development of the legislation, suggested what is currently in place is a hybrid of old and new legislation. He suggested it may have been more beneficial not attempt to introduce four new Acts at the same time unless there was support, particularly in regard to the budget necessary, to ensure all Acts would be proclaimed at the same time. Dr Gordon suggested the experience of legislation taking an extended period of time to be proclaimed occurs fairly regularly in British Columbia. A difficulty when this occurs is that while legislation is waiting to be proclaimed society is changing and slowly over time it becomes redundant.

Representation Agreements

The Representation Agreement Act was proclaimed ten years ago in the context of much opposition from the legal community. At a number of points, prior to proclamation, the Act was nearly withdrawn however following strong advocacy from disability groups a compromise was brokered by the Attorney General. It is acknowledged by those in the disability community that the compromise that was reached did not resolve the concerns the legal community had with the agreements. As a result it would seem the legal community has not embraced representation agreements or promoted them as a planning tool for people who may lack capacity in the future. Legal practitioners by and large do not promote the Section 9 agreements which require a lawyer to witness the signatures to be valid. It was suggested that instead legal practitioners have continued promoting the need for Powers of Attorney (POA). Initially it was the intention that representation agreements would replace POA entirely. Similarly my discussions with health professionals clarified that the Department of Health have also not embraced the representation agreement as a tool for future planning for medical treatment. The Department of Health has continued to pursue the development of a legal tool specifically for health planning such as an advanced care directive. Strong advocates for the Representation Agreement Act are disappointed that the usefulness and scope of the representation agreement has not been realised over the last ten years.

One set of stakeholders is very concerned about representation agreements are those supporting vulnerable seniors. It expresses concern that there is a lack of accountability for the representatives. The legal community argues that people are more vulnerable with a representation agreement than with a POA because a representation agreement is only a legal contract and doesn't come with the same fiduciary obligations that are inherent in the POA. However it could be asserted that having a fiduciary obligation does not safeguard people from financial exploitation. It is well documented
that elder abuse occurs when POA are in place. Some disability organisations argue that abuse would be less likely to occur with a representation agreement because more education is available to representatives about their role, through the work of agencies such as NIDUS, than is occurring regarding the role of the POA in British Columbia. NIDUS is a not for profit organisation established as a voluntary register of representation agreements in British Columbia. NIDUS provides community education about all aspects of representation agreements. Ms Joanne Taylor from NIDUS reported there are currently 5000 representation agreements registered in British Columbia.

The Public Guardian and Trustee confirmed that they have been responding to complaints and concerns raised regarding representation agreements. They did not have statistics available on how many complaints have been made with regard to representation agreements over the last ten years. However it was suggested that reports of abuse by representatives is no more prevalent than by attorneys. The Public Guardian reported that to date there has not been a significant case taken to court regarding financial exploitation by a representative. This had been anticipated by some legal professionals when the Representation Agreement Act was first introduced.

Guardianship

The Public Guardian and Trustee provides a range of financial and personal care services for adults under a number of different roles including Committee of Estate, Committee of Person, Power of Attorney, Representative, Litigation Guardian and Pension Trustee. For the majority of clients the Public Guardian and Trustee is Committee of Estate under the Patients Property Act with the responsibility for the legal and financial management of the client's affairs. When the Public Guardian and Trustee acts as Committee of Person it is a substitute decision maker for the health and personal care needs of the client. The Public Guardian reported that they have 114 adult clients for whom they act as Committee of Person out of 8643 clients in total (Annual Report 09/10).

The Public Guardian and Trustee is appointed Committee in one of two ways. By a Certificate of Incapability being issued by a Director of a Mental Health Facility or Hospital Psychiatric Unit and by order of the Supreme Court of British Columbia. A Certificate of Incapability is only used for Committee of Estate not Person.

It is possible for a private individual to become committee for a person who is unable to make their own financial or personal care decisions. The individual has to make an application to the Supreme Court of British Columbia to be appointed. It is necessary to have a lawyer for this process who gathers the necessary evidence and legal documents to progress the application. Legal fees are not set but the cost to the individual is usually from between $2500 - $5000 These legal fees may come from the client's estate eventually if the court determines this is appropriate at the hearing.

Supported Decision Making

The Community Living movement has been educating Canadians on the principles and
practice of supported decision making for over ten years. Ms Faith Bodnar, Executive Director of BC Association for Community Living, provided me with a teaching resource which clearly defined supported decision making and how it could be implemented. The following information comes directly from the teaching resource provided by Ms Bodnar.

Supported decision making is about respecting the fundamental right of all people to be self determining. All people have the right to make decisions about how they want to live and to have those decisions respected. This is called self determination. Traditionally people with disabilities have had few opportunities to be self-determining and are viewed as receivers rather than determiners of programs and services.

Supported decision making is a process that respects the rights of people with disabilities to make decisions. It is based on the person's values, dreams, goals and wishes. It says that we are connected with others who support us to make decisions but that we are in charge of the decision making processes that affect our lives.

Supported decision making is also about relationships. It reveals a new way of looking at our relationships with people with disabilities so that they can share, dream and make decisions about their own lives. It is based on equality, citizenship rights and the responsibility we have to support people to make and carry out their own decisions.

Supported decision making is about removing the barriers that prevent people from being able to exercise their human right to make decisions. Removing barriers can mean providing information in a way that the person can understand or using plain language or providing an interpreter.

We all have the right to the kind of support we need to participate and make decisions. A person with a disability may use their rights differently and may need more support.

A foundational principle of supported decision making is the belief that all people are competent. A number of people I met while travelling were ideologically opposed to guardianship because they viewed guardianship as a state structure which enshrined practices which violated this principle.

So a clear Definition of Supported Decision Making from the Canadian Association for Community Living is:

"A process of acting with an individual to discover their values, interests, talents and gifts in order to support them to choose the way they want to live their life."

When speaking with people from disability organisations about supported decision making they were much less concerned with what the process itself looked like but whether the process used facilitated the individual discovering their values, interests, talents and gifts. Initially I was frustrated by this focus because wanted to know how to do supported decision making. Eventually, I could see that without understanding the principles of supported decision making it didn't matter what method was used because it inevitably reverted back to substitute decision making. Without the right foundation and approach models of supporting people to make decisions are not successful.
The community living movement in Canada pictorially represent supported decision making using the following diagram:

In their view there are three essential components: Values and Principles, Decision Making Process and Relationships. When I left Australia I was very focussed on the Decision Making Process but came to realise that without relationships there is no one to support the person to make the decision. Equally if the process if not focussed on the principles and values of supported decision making it ends up not being supported decision making but rather becomes substitute decision making.

Principles and Values of Supported Decision Making

As defined by Canadian Association for Community Living:

- All humans have "will". The human will is an inner drive to choose or determine how you live.
- Each person has the right to self-determination: the right to make decisions.
- Decision making is a fundamental human right. (UN Convention of Rights of Persons with Disabilities).
- We have a duty to respect the decisions that other people make and help them achieve their dreams.
- A person's right to make decisions is not limited or removed by disability.
- The right to make decisions includes the right to have the support needed to make
decisions and to let others know about them.

- In Supported Decision Making, the individual is the centre of the decision making process.
- Decision making is based on building relationships of trust between the person and their supporters.
- Decision making is about process not outcomes.
- The Supported Decision Making process is based on the idea that when someone helps you make decisions, it must be done with respect for you and your wishes.

Relationships

In analysing the relationship between the person who has reduced capacity and the person providing support to make a decision it was evident that the best supporter is someone who knows the individual very well. From discussions with people who are engaged in supported decision making it became clear that without meaningful inclusion, that is people having strong, close, enduring relationships in their life, supported decision making is fairly limited.

Reflections

Inclusion has been discussed for a long time in the disability sector but as discussed earlier for supported decision making to be successful it needs to be more than rhetoric. An organisation I met with in Canada called Planned Lifetime Advocacy Network (PLAN) was set up to try and bridge the gap between the rhetoric of inclusion and the difficult reality. PLAN's vision for everyone, including people with disabilities, is to be able to have a good life. They define a good life as having family and friends who love us, a place of one's own, financial security, being able to participate in decision making and the ability to contribute to society. The work that PLAN are doing to assist people to create social networks that are meaningful is inspiring and I believe that people with disabilities in Australia would benefit from agencies sharing a similar vision to that being lived out by PLAN.

Although models of supported decision making have been used in British Columbia for over ten years it was very difficult to obtain any qualitative or quantitative research that had been done into any aspect of the decision making process. Nor was I able to locate research on methods of actually providing support to people with limited capacity. This made discussion of the benefits and challenges of such models purely subjective and theoretical rather than based on more concrete data and evidence.

There is an international symposium which will occur in April 2011 in Vancouver hosted by the Peter Wall Institute of Advanced Studies at the University of British Columbia. It will focus on the conceptual foundations of moral and legal personhood, the definition and criteria for legal capacity, the implications for law and policy related to adult protection, substitute and supported decision making and the emerging social and legal forms of support and reasonable accommodation that enable people with significant cognitive or
psychosocial disabilities to maximize their legal capacity and social citizenship. This symposium hopes to bring together people working in the areas of capacity, personhood and decision making from all over the world to lay the foundation for a shared and cohesive framework for research and development of law, policy and practice in this area. This will be a significant development in enabling more substantive discussions and debate regarding the benefits and challenges of supported decision making in the future. This is a necessary next step in enabling supported decision making to move from being primarily an ideological construct to an evidence based practice.

References


Website of Public Trustee and Guardian of British Columbia
http://www.trustee.bc.ca/news_information/Adult Guardianship.htm


Conclusions

Supported Decision Making

- At this moment in time supported decision making is primarily an ideological construct rather than an evidence based practice. The values and principles of supported decision making can be clearly articulated. However, future research is needed to answer the questions stakeholders have regarding how to best support someone to make their own decisions.

- Models or instruments of supported decision making such as representation agreements and co-decision making orders will be misused as a tool of substitute decision making unless those using them are clear about the philosophical differences between the two. It is therefore of concern that little education is being offered to people establishing these agreements to ensure they are aware of the values and principles of supported decision making.

- Supported decision making best occurs in the context of trusting, meaningful, long term relationships. This would suggest it is best situated within the community sector rather than being facilitated by government agencies such as the Public Guardian.

- Supported decision making goes hand in hand with the principles of inclusion and citizenship. In an attempt to establish supported decision making tools in Australia there has to be consideration and evaluation of whether the individuals for whom these tools are being suggested have access to meaningful relationships outside of paid carers.

Guardianship in NSW

- The current legislation in NSW is in line with the principles of the United Nations Convention on the Rights of Persons with Disabilities. However, there are guardianship processes which could be changed that would result in people having greater freedom and the ability to exercise their legal rights to a greater extent.

- The most significant change would be the assessment of capacity each time a decision needs to be made involving a person under guardianship.

- There is a tremendous benefit in having an independent government agency who can make substitute decisions for someone when it is determined they are unable to make the decision themselves. This model offers consistency, an unbiased fair process of decision making, the accumulation of a body of knowledge and expertise in the area of complex substitute decision making which benefits the person. The benefits to the person include protection against abuse, neglect and exploitation and even against the apathy of service providers who resist supporting the people who are most challenging. These roles could be encapsulated under the umbrella of advocacy.
• It can be concluded that the role of the NSW Public Guardian as an advocate is vital. Any development that would increase the ability of the Public Guardian to offer more systemic advocacy for clients would further the benefits currently offered.

• The Guardianship Tribunal that exists in NSW is tremendously valuable. It offers a fair process, is independent and accessible to people who are most vulnerable. The establishment of a Tribunal instead of a High Court to make a determination regarding a person's capacity and subsequent need for a guardian is envied by many jurisdictions overseas.

• The cost of many Court processes overseas makes accessing the appointment of a guardian or independent review of decision prohibitive. The fact that the Guardianship Tribunal operates at no cost to participants is so important.

• Finally the expertise of panel members from the Guardianship Tribunal, that are able to facilitate a meaningful process for people who have challenges with regard to capacity, is commendable. This process affords people a greater level of dignity than is found in other jurisdictions overseas when the person is unable to participate in forums that determine whether they will have a substitute decision maker appointed.

Development and Implementation of New Legislation

• There are benefits and challenges with each legislative framework and system of guardianship. Each is trying to find a balance between the competing principles of the rights of the individual and duty to protect vulnerable people.

• It was evident from the experiences in other jurisdictions that a legislative change does not necessarily bring about a cultural shift. If people don't understand the legislation, and why it was changed, it won't bring about cultural change. This means that the implementation of new legislation requires a collaborative approach that consults widely with stakeholders.

• It also requires necessary funding to ensure people can be educated as to how and why the legislation has changed.

• If no agency is responsible for the implementation of new legislation it is extremely difficult to promote change over the long term. Legislative change requires vision and direction to be set by an agency.

• Determining the benefit of legislating supported decision making has been extremely difficult. Primarily because there is so little research and data available to substantiate arguments for and against. None of the jurisdictions were able to clarify how many supported decision making agreements were in place let alone quantify their value to stakeholders. It has not been possible to develop a clear conclusion in relation to the value of legislating supported decision making models such as representation agreements.
There is a strong focus in jurisdictions overseas and in Australia to increase people's decision making rights when it relates to personal care and welfare decision making. The cultural shift which is occurring in these areas is not translating in the areas of financial decision making.

It would seem more education and dialogue is needed to understand why the cultural shift which is creating a continuum of options for people with regard to personal care decision making is not creating options for people to be supported to manage their own finances.
Recommendations

Supported Decision Making

- Supported decision making should be facilitated by members of the community who are supporting people with disabilities in other areas of their lives.
- Supported decision making necessitates people with limited capacity having meaningful long term relationships outside of paid staff. Agencies that support people with limited capacity must be promoting opportunities for the development and maintenance of these relationships as part of a person centred approach.
- The NSW Public Guardian could have a role in providing education to members of the community supporting people with limited capacity. Education would focus on the principles and values of supported decision making.
- Research into the process and methods of supported decision making is needed. Any trial of supported decision making must include data collection and involve formal research to evaluate the model objectively. In doing so it will add to an international body of knowledge being developed on alternatives to substitute decision making.

Guardianship in NSW

- That capacity assessment becomes decision specific in NSW for a person under guardianship.
- If this is not able to occur under the current legislation that consideration is given to changing the legislation to enable decision specific capacity assessment to occur. In doing so we would be making our guardianship practice least restrictive with regard to the legal rights of our clients.
- Should capacity assessment become decision specific I would recommend the Guardianship Tribunal continue their role in determining a need for a guardian or financial manager to be appointed. The hearing would determine if capacity issues were present which would warrant a substitute decision maker to be appointed. It would be determined at the time a decision was needed whether the person was capable of making the decision with support or whether a substitute decision maker would be necessary.
- Should capacity assessment become decision specific I would also recommend the development of a guideline for guardianship staff to follow when it is believed a client under a current guardianship order is capable of making a decision themselves. The guideline would clarify whether decisions can be recorded in the database as made by the person. It would also clarify the communication process between the person and their guardian and how that particular decision is relayed to other parties.
- The role the Guardianship Tribunal has in providing one off consent to medical
and dental treatment be expanded. By increasing the capacity of the Guardianship Tribunal to provide one off consent it would decrease the need for guardianship to be involved. This would be a less restrictive option for people with limited capacity that works well in a number of other jurisdictions through the provision of Acts such as Health Care Consent Act in Ontario.

Development and Implementation of New Legislation

- Future guardianship legislation should sit under the authority of the Department of Justice and Attorney General.
- The NSW Public Guardian should be involved in setting a clear direction for future legislation and practice with regard to substitute decision making in our jurisdiction.
- The implementation of any new legislation should be the responsibility of one agency enabling accountability in the long term which benefits all stakeholders.

Financial Matters

- There is a clear need for the establishment of an agency who would support people with limited capacity to be able to manage their own finances. A new model of service delivery would need to be created which enabled people to be given shared responsibility with regard to their financial matters. The goal would be to assist clients to develop their financial management skills with a view to taking over part or all of their financial decision making in the future. The agency could work alongside the NSW Trustee and Guardian to assist in reducing the number of people under long term financial management orders that may be appropriate to be discharged if adequate support was in place.