



Supported Decision Making, Legal Capacity and Guardianship

Implementing Article 12 of the Convention on the Rights of Persons with Disabilities in the Australian Capital Territory

Advocacy for Inclusion

August 2012

About Advocacy for Inclusion

Advocacy for Inclusion acknowledges the Ngunnawal people as the traditional owners of the land on which we work.

Advocacy for Inclusion provides individual, self and systemic advocacy services for people with disabilities. We provide information, education, and representation to effectively advocate for positive and inclusive outcomes for people with disabilities.

We act with and on behalf of individuals in a supportive manner, or assist individuals to act on their own behalf, to obtain a fair and just outcome for the individual concerned.

Advocacy for Inclusion works within a human rights framework and acknowledges the United Nations *Convention on the Rights of Persons with Disabilities*, and the *ACT Human Rights Act*.

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“Getting the Guardianship Order wasw [sic.] the biggest mistake we've made. It's intrusive, degrading, and not applied uniformly across the ACT. Once you have an Order on a person, you're trapped within the legal system. Should you wish to relinguish [sic.] an Order, it defaults to the Public Trustee.”

“The Guardianship Tribunal is extremely one-eyed and rigid and not at all open to other modified arrangements.”

“It is difficult to bring up someone else's child, even if they are in your family. Access to counselling or a support group would have been useful. As we approach the end of the period for which the order was made we would like some help to assist the young person to move out of our care and into some sort of independent living arrangement.”

“Disability should show greater understanding of the obligations and rights of Guardians.”

[I want to be] “given a chance to say what I need to say about what I can do spending my money that I earn by working every day.”

“I get the general impression that many service providers, especially in the medical field, assume that if a person has any cognitive limitation or even any disability they automatically need a guardian to make decisions for them. Often people think that the solution to a person's problems is getting them a guardian.”

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Executive Summary

In light of Australia's obligations as a signatory to the United Nations *Convention for the Rights of Persons with Disabilities* (CRPD),¹ Advocacy for Inclusion recommends major reform of The *ACT Guardianship and Management of Property Act 1991*. This report discusses a long term transition towards Supported Decision Making models as a human rights compliant alternative to guardianship practices. It was prompted by a survey conducted by Advocacy for Inclusion on guardianship in the ACT.

Guardianship legislation is the norm across all Australian states and territories. However, there are some major human rights issues with the very concept of guardianship and substitute decision making, which denies many people with disabilities the right to make decisions about their own lives.

Article 12 of the CRPD requires signatories to support people with disabilities to effectively exercise legal capacity on an equal basis with other members of the community, and have autonomy in regards to property, health and lifestyle. Current guardianship legislation directly contradicts these obligations. There are also major concerns regarding a lack of procedural fairness afforded to people subject to guardianship applications, including issues with transparency, accountability, meaningful review processes and access to independent support.

Supported Decision Making models are relatively new frameworks for supporting people with cognitive disabilities to make significant decisions and exercise their legal capacity. Where guardianship practices cannot, Supported Decision Making offers a framework that promotes the skills, strengths, knowledge and experience of people with disabilities, to assist them to maximise their autonomy, inclusion and contribution to the community. These models are currently used in parts of Canada, the UK and are being trialled in South Australia. They should be developed in the ACT as human rights oriented alternatives to substitute decision making practices.

The disability services landscape will transform with the introduction of the National Disability Insurance Scheme (NDIS). It is an exciting and advantageous time to consider how best we might empower the rights of our citizens with disabilities. Introducing Supported Decision Making into this new environment will maximise the benefits of the NDIS by improving the social capacity for people with disabilities to have their decisions recognised and valued. This will place the NDIS in a better position to be directed by the people it is targeted towards.

The transition towards Supported Decision Making must contend with long held community and professional assumptions about the capacity of people with disabilities. Moving towards human rights oriented models will be a process of transition. It will require training and awareness raising at multiple levels of the community as well as the development of programs and resources to assist our community to progress towards a more inclusive society. This report recommends a path of transition towards full implementation of Article 12 of the CRPD. It is time to take up the challenge!

¹ United Nations General Assembly, 13 December 2006 *Convention on the Rights of Persons with Disabilities*

Guardianship Survey

Advocacy for Inclusion conducted a Guardianship survey to begin an exploration of guardianship in the ACT. Specifically, we set out to collect data about the number of people under a plenary (total) Guardianship Order in the ACT, as well as the proportion who have the Public Advocate as a Guardian. The survey was also intended to collect some qualitative information to inform our work on Supported Decision Making.

The survey responded to the absence of information on Guardianship generally, and in regards to actual guardianship orders in the ACT. The ACT Civil and Administrative Tribunal (ACAT) does not adequately record the number, type or progress of guardianship orders in the ACT, making it very difficult to address guardians, or people under guardianship orders as a group. While it is acknowledged that the ACAT is working to redress this, the gap in ACT records needs attention.

Methodology

Advocacy for Inclusion conducted two surveys: one for people who have a Guardian (protected persons) and one for Guardians. They were both opt-in, online surveys. This was done to improve accessibility. Hard copies were also available. People were assisted in undertaking the survey if they requested it.

Results

The number of responses was smaller than hoped, so no quantifiable conclusions can be drawn from this survey; however, it does provide some valuable qualitative insights into the experience of guardianship in the ACT.

For these reasons, discussions and recommendations in this report are based primarily on existing Australian and international research and literature. The insights gained from the survey are incorporated throughout alongside knowledge from our front line advocacy work.

People with a guardian were underrepresented in the respondents - an apt reflection of the isolation and social silencing our work aims to highlight.

All respondents who had a guardian said that they want to make decisions for themselves. Most said that they do not want a guardian and that their guardian does not ask them what they want. Most also said that the Tribunal did not speak with them directly or clearly ask them what they wanted. Others said they did not attend the Tribunal at all.

Most guardians reported that the order was plenary and said they felt a guardianship order would always be necessary; however those who tried to have an order removed or partly removed were unsuccessful.

Alarming, most responses indicate that guardians and protected persons did not have access to a worthwhile and systematic review process, some stating that they had never been to a review at all even when they had been a guardian for more than 3 years. Many guardians said that they felt they did not have enough information prior to undertaking the order and half reported feeling unsupported in their guardian role.

This information provides insight into significant issues experienced by people in the ACT in relation to guardianship orders. Further funded and sustained research to understand better the experiences of guardianship in the ACT on a wider scale would be extremely worthwhile.

Recommendations

1. ACAT to record the nature, number, and specifics of every guardianship order granted in the ACT, as well as the details of review processes.
2. ACAT, in collaboration with advocacy organisations, to develop a formal system that ensures all people subject to guardianship applications can readily access advocacy support, independently of the guardian, before, throughout and after a guardianship order is in place.
3. ACAT, in collaboration with advocacy bodies, to create mechanisms for transparent hearings at the Guardianship Tribunal, in which those subject to guardianship applications have access to independent representation and information.
4. Remove the medical approach to defining legal capacity from ACT guardianship legislation, including terms “condition” and “disability status.”²
5. The ACT and ACAT to develop appropriate mechanisms by which the finding of legal incapacity is limited to certain decisions, situations and timeframes, recognising decision making capacity as existing on a continuum.^{3 4 5}
6. In line with good practice models operating in the UK and Ontario and commended by the World Health Organisation, a definition of legal capacity should be outlined and legislatively transparent, measured by whether an individual:
 - a) understands the information relevant to making a particular decision;
 - b) uses and weighs that information as part of the decision-making process;
 - c) appreciates the reasonably foreseeable consequences of the decision and of not making a decision;
 - d) makes the decision voluntarily; and communicates the decision (whether through speech, writing, sign language or any other means), using the most appropriate communication form to that person.^{6 7}
7. ACAT to develop capacities for transparent and systematic review of standing guardianship arrangements, including allowing for an order to be rescinded.
8. Review accountability measures under guardianship orders, including transparency mechanisms for substitute decisions, and complaint processes for those under orders.⁸
9. The ACT to investigate adult protection legislation, which may provide some of the safeguards currently considered necessary under guardianship without the appointment of a guardian.⁹

²Attorney Generals Department NSW, 2010, *Are the Rights of People whose Capacity is in Question being Adequately protected?*, People With Disabilities & Blake Dawson Waldron Lawyers

³Ibid

⁴Bach, M., 2007, *Supported Decision Making- Lessons from Canada*, Canadian Association for Community Living

⁵International Guardianship Network, 2010, *Yokohama Declaration*, http://www.international-guardianship.com/pdf/IGN-Yokohama_Declaration_2010.pdf.

⁶Bach, Op. Cit.

⁷Bach, Op. Cit.

⁸International Guardianship Network, Op. Cit.

⁹Brayley, J., 2009, *Supported Decision Making in Australia: Presentation Notes*, http://www.opa.sa.gov.au/documents/08_News_%26_Articles/Supported%20Decision%20Making.pdf -- Adult protection places less emphasis on capacity and more on vulnerability. This is an important step in recognising that vulnerability is not equivalent to incapacity, and that removing decision making rights is not a proportionate or effective response to risk of abuse or neglect.

10. Reform guardianship processes to comply with human rights obligations under the CRPD.^{10 11}
11. The ACT to amend guardianship legislation to promote the use of Supported Decision Making models¹² instead of appointing a substitute decision maker. The ACT to affirm decision making rights of the focus person and the role of supporters.¹³ This should be done with a view towards facilitating the removal of legislation entirely in the long-term future, replaced with Supported Decision Making models that function less formally in the community.
12. The ACT to develop a framework in legislation to restrict substitute decision making and the finding of legal incapacity as last resort option, only to be used for specific decisions and limited time frames when supported decision making options have been properly tried and exhausted.¹⁴ As recommended in *Essential Principles: Irish Legal Capacity*, a framework should include the following expectations:
 - a) The best efforts must have been made to communicate with the person about the decision, through all possible means including unconventional communication;
 - b) Every effort must have been made to understand the person's will and preferences;
 - c) If there is no existing support network for that person one should be developed if possible;
 - d) Every effort must have been made to provide information in a manner that the person can understand and all means of support (including advocacy) should have been provided in order to help the person make a decision.¹⁵
13. The ACT to resource a community organisation to undertake a researched trial of Supported Decision Making in the ACT, building upon, but not replicating, the South Australian pilot.¹⁶
14. The ACT to ensure legal professionals, government officials, the Public Advocate and ACAT are fully trained in Supported Decision Making and obligations under the CRPD.
15. The ACT to resource the community sector to train people with disabilities and their supporters on using Supported Decision Making successfully.
16. The ACT to facilitate the development of non-statutory circle and peer network Supported Decision Making models in the community by funding community agencies to develop these models.
17. Government and agencies to develop appropriate safeguards for any formal Supported Decision Making trial.

¹⁰ Carter, B., 2010, Adult Guardianship: Human Rights or Social Justice, Thomson Reuters, *Journal of Law and Medicine*, 18(1):143-155

¹¹ Mental Disability Advocacy Center, *Analysis of Russian Legal Capacity System for Persons with Mental Disabilities: Towards Implementation of Article 12 of the UN CRPD*, <http://www.mdac.info/en/resources/analysis-russian-legal-capacity-system-persons-mental-disabilities-towards-implementation>

¹² Victorian Law Reform Commission, 2012, *Guardianship: Final Report 24*, Melbourne

¹³ Brayley, J., Op. Cit.

¹⁴ *Essential Principles: Irish Legal Capacity Law*, 2012, http://www.nuigalway.ie/cdlp/documents/principles_web.pdf

¹⁵ Ibid.

¹⁶ ADACAS has applied for funding to undertake such a trial.

- 18.** The ACT to fund the development of a program for families and supporters who may be involved in Supported Decision Making agreements. Like the Canadian Community Living Project, the emphasis should be on valuing skills, talents and interests. This should be co-designed with people with disabilities.¹⁷
- 19.** Government in collaboration with community sector and consumers to produce a campaign on educating the public on the rights and abilities of people with disabilities, in line with the most successful extended campaign for mental illness awareness Like Minds, Like Mine in New Zealand. This should be co-designed with people with disabilities.¹⁸
- 20.** Disability Inclusion and Awareness Training to be mandatory for people working in the disability sector.¹⁹
- 21.** The ACT to develop a program to track improvements or changes in community attitudes towards people with disabilities, which is undertaken consistently over the long term.
- 22.** The ACT to fund resources for community organisations to distribute to workplaces, health service providers, housing providers, legal service providers and the general public. Resources should outline what Supported Decision Making is, how it works, why it is being explored and how to support it. These must include plain English pamphlets about Supported Decision Making. These materials should link to organisations running or facilitating training and Supported Decision Making.
- 23.** Government to fund crucial NDIS preparation training as recommended in the Advocacy for Inclusion Budget Submission 2012-13, recognising that the transition to an NDIS will require dedicated consumer oriented preparation, and that the NDIS is an opportune time to begin the transition to Supported Decision Making models.
- 24.** The relative 'newness' of Supported Decision Making models should be viewed positively. The ACT is in a position to pioneer working models of support.

¹⁷ Community Living Project, <http://www.clp-sa.org.au/node/4>

¹⁸ The New Zealand Ministry of Health Like Minds, Like Mine project <http://www.likeminds.org.nz/page/5-home> - the project addressed stigma and discrimination about mental illness using advertising campaigns and awareness raising activities carried out by consumer led groups. Tracking surveys indicated that attitudes had improved.

¹⁹ Thompson, et. al., Op. Cit.

Article 12²⁰

Equal recognition before the law

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

²⁰Article 12, United General Assembly, 13 December 2006 *Convention on the Rights of Persons with Disabilities*

Background

As a signatory to the CRPD, meeting our obligations to protect the rights of people with disabilities is an urgent and necessary task for Australia and the ACT. We are required to address the ways in which our local and national laws interact, reflect, or fail to reflect our human rights obligations to people with disabilities. Guardianship legislation is one significant area, which upon proper review can bring us closer to fulfilling these obligations. This should be done in light of Supported Decision Making models, which is a skills building model of support that empowers people with cognitive disabilities to retain and exercise their decision making rights.

Throughout history people with disabilities have been undervalued, denied the most basic of human rights and excluded from society. In recent decades society has shifted from the institutionalisation of people with disabilities to more inclusive community based practices. Political and social attitudes around the world continue to change in regards to how society can best empower and represent its citizens with disabilities.^{21 22} There is still a way to go, with substitute decision making models, known as guardianship, continuing to have a dominant influence on the disability landscape across Australia.

While Australian legislative discourse may show characteristics of person-centred, human rights principles, this is not adequately reflected in the related law or disability service practice. For example, the *Guardianship and Management of Property Act* and *Mental Health Act* 1991 in the ACT stipulate 'best practice' expectations; however there is little to reflect human rights obligations or outline how they might be fulfilled.

Current guardianship legislation is characterised by a paternalistic²³ and out dated preoccupation with the *protection* of people with disabilities.²⁴ By finding a person to have legal incapacity, it removes recognition of an individual in the eyes of the law, denies them the right to operate autonomously and have their decisions legally recognised and places their decision making rights in the hands of others. Within this model the concept of decision making is black and white: either one has it or they do not. This is unrealistic and fails to accommodate the grey areas of decision making ability, which varies across time and different contexts. Substitute decision making is a deficits based model that cannot harness any strengths in an individual's knowledge, experience and ability.

Furthermore, orders are notoriously difficult to remove or comprehensively review, locking a person into orders for long periods of time and, indeed for many, for their whole adult life.

In sharp contrast to this, the CRPD recognises the autonomy, dignity and freedom of people with disabilities. Article 12 of the CRPD states that it is an inalienable right for people with disabilities to enjoy equal recognition and legal capacity before the law. Meeting these obligations requires substantial reconsideration of guardianship approaches that have become the norm in all States and Territories in Australia, and are legislated in the ACT under the *Guardianship and Management of Property Act* 1991,²⁵ and associated legislation such as the *Mental Health (Treatment and Care) Act* 1994.²⁶

²¹ Australian Social Inclusion Board, 2008, *National Mental Health and Disability Findings*, <http://www.socialinclusion.gov.au/sites/www.socialinclusion.gov.au/files/publications/pdf/findings-mental-health-disability-sector-consult.pdf>

²² Carter, Op. Cit.

²³ Carter, Op. Cit.

²⁴ Victorian Law Reform Commission, Op. Cit.

²⁵ *Guardianship and Management of Property Act* 1991, Australian Capital Territory

²⁶ *Mental Health (Treatment and Care) Act* 1994, Australian Capital Territory

Society is moving away from these restrictive structures towards a greater focus on *promoting* the rights of people with disabilities to have as much direction over decision making as possible.²⁷ Countries such as Canada and the UK have taken a global lead on developing human rights based legislation and practices with regards to decision making for people with disabilities, which include Supported Decision Making principles and models. South Australia and Victoria have begun paving the way for Supported Decision Making practices in Australia.

Significantly, the 2012 Victorian Law Reform Commission report *Guardianship and Administration Act 1986* (Vic), which is equivalent to the ACT legislation, recommended substantial change to legislation in order for Victorian guardianship law to reflect human rights principles outlined by the CRPD.²⁸ The *National Disability Strategy* (NDS) stipulates that restrictive legislation must be reviewed, that Supported Decision Making processes must be developed, and that there must be accountability for current and future guardianship or substitute decision making practices.²⁹

It is pertinent that the ACT keep up with these developments, particularly with the National Disability Insurance Scheme (NDIS) about to be introduced. Standing as the largest reform to disability in a lifetime, the NDIS must be human rights compliant if it is to become a sustainable, relevant and workable scheme into the future. The NDIS is intended to set the scene for person-centred and self-determined support models that enable people with disabilities to “fulfil their potential as equal citizens.”³⁰ However, under a guardianship order a person loses the right to negotiate with institutions and professionals on their own behalf. For this reason, the legislation must be reworked to promote people with disabilities as the drivers of their own lives in order to maximise the benefits of the NDIS.

Supported Decision Making models, which are strengths based and human rights-oriented, are the way forward. They involve an arrangement in which the focus person engages in consultations where they are supported to address, weigh and conclude specific decisions with support from others.³¹ It is certain that some informal Supported Decision Making practices are already in place in the ACT;³² however, they operate under the current guardianship legislation, where banks and institutions more readily recognise substitute decision making orders. Advocacy groups that encourage Supported Decision Making models might offer training and workshops in Supported Decision Making practice, but face an uphill battle while guardianship is still the ‘recommended’ and culturally accepted model of decision making.

Supported Decision Making models will have greater reach if worked into a formal service strategy, as has been recommended in Victoria.³³ Removing legislative reliance on a view of ‘legal capacity’ will enhance human potential. Encouraging Supported Decision Making relationships will offer greater protection from vulnerability born from isolation by placing emphasis on mutual, trusting relationships.³⁴

Developing an accurate picture of how guardianship is operating in the ACT will be part of transitioning towards human rights models and implementing Supported Decision Making. This paper will explore how the ACT can work towards full implementation of CRPD Article 12 through a transition from guardianship practices to Supported Decision Making models.

²⁷ Ibid.

²⁸ Victorian Law Reform Commission, Op. Cit.

²⁹ Ibid.

³⁰ *National Disability Strategy 2010-2020*, 2011, Commonwealth of Australia

³¹ South Australian Office of the Public Advocate, 2011, *Developing a Model of Practice for Supported Decision Making*, South Australia

³² Ibid.

³³ Victorian Law Reform Commission, Op. Cit.

³⁴ Chartres, Op. Cit.

Guardianship and capacity

Along with jurisdictional norms in Australia, the dominant model of decision making for people with intellectual or cognitive disabilities in the ACT is substitute decision making, or guardianship. The Public Advocate ACT states that:

“Adults with decision making disabilities require the appointment of a substitute decision maker to take responsibility for their personal, health, financial, property and other affairs.”³⁵

Central to the application of a guardianship order under the *Guardianship and Management of Property Act 1991* is the finding of legal incapacity. That is, guardianship orders are made when an individual is deemed unable to make decisions about the course of their own life and are unable to take legal responsibility for these decisions. Under the *Powers of Attorney ACT 2006* people may nominate a guardian in the event that they are someday deemed to lack legal capacity.

Under ACT legislation, a guardian’s action is given the same legal weighting as if the person under a guardianship order had acted themselves.³⁶ In contrast, the person under a guardianship order is no longer able to make legally recognised decisions. Effectively, a person under a plenary guardianship order must obtain the authority of their guardian to make decisions. A guardian may be appointed to make decisions about the person’s education, employment, accommodation, and medical, legal and financial affairs. Decisions made by the person subject to the orders effectively become illegitimate. Living in a “civil coma”³⁷ is a powerful but realistic description of what it can be like living under guardianship orders.

Appeals against guardianship orders can be made to the Supreme Court, though a review process usually takes place through the ACAT.³⁸ A national picture gathered from Disability Advocacy Network of Australia members’ feedback indicates that guardianship orders are typically plenary, covering all decisions an individual might need to make. Once in place orders are unlikely to be rescinded by any means such as review by the Tribunal, request by guardian or person under guardianship order, or with changed decision making skill level. Our direct advocacy work is consistent with these findings.

“Getting the Guardianship Order wasw [sic.] the biggest mistake we’ve made. It’s intrusive, degrading, and not applied uniformly across the ACT. Once you have an Order on a person, you’re trapped within the legal system. Should you wish to relinquish [sic.] an Order, it defaults to the Public Trustee.”³⁹

“I tried to have the financial order removed and my request was refused.”⁴⁰

While across Australia, common law operates on *presumed capacity* — that is, the onus is on those seeking a guardianship order to prove an individual is incapable of making a decision — a workable and applicable definition or effective assessment frameworks for defining legal capacity is unclear and varies between the States.⁴¹

³⁵ ACT Public Advocate, *Substitute Decision Making*, http://www.publicadvocate.act.gov.au/guardianship/substitute_decision_making

³⁶ O’Brien, J., 1999, *Community Engagement: A necessary Condition for Self-determination & Individual Funding*, Responsive Systems Association

³⁷ Mental Disability Advocacy Center, 2011, *Legal Capacity*, <http://www.mdac.info/en/legal-capacity>

³⁸ International Guardian Network, *Global Table on Guardianship*, <http://www.international-guardianship.com/igs.htm>

³⁹ Advocacy for Inclusion Survey Respondent (guardian)

⁴⁰ Ibid.

⁴¹ Victorian Law Reform Commission, Op. Cit.

ACT legislation does not provide clear guidelines on how impaired decision making capacity should be proved or determined. Furthermore, ACAT does not sufficiently record the number, type or process of guardianship orders in the ACT. For these reasons, how a person's capacity is determined in the ACT is unclear.

There are cases in the ACT where guardianship orders are placed on people who have not been adequately involved or informed throughout the tribunal processes; they are given little opportunity to confirm their capacity or express their wishes in relation to the order. We must question how stringently this burden of proof or the presumption of capacity is upheld in the ACT and whether people with disabilities are being afforded a fair hearing.

Moreover, it is apparent that no formal system exists to ensure those under guardianship are provided proper legal and informational support throughout the initial stages of a guardianship order request. If guardianship orders do operate on a presumption of capacity, then it is necessary that people with disabilities be given appropriate support and space to negotiate the terms of the order.

Recommendation 1: ACAT to record the nature, number, and specifics of every guardianship order granted in the ACT, as well as the details of review processes.

Recommendation 2: ACAT, in collaboration with advocacy organisations, to develop a formal system that ensures all people subject to guardianship applications can readily access advocacy support, independently of the guardian, before, throughout and after a guardianship order is in place.

Recommendation 3: ACAT, in collaboration with advocacy bodies, to create mechanisms for transparent hearings at the Guardianship Tribunal, in which those subject to guardianship applications have access to independent representation and information.

According to the *Guardianship and Management of Property Act 1991 (ACT)*, a person has impaired decision making ability when “the person’s decision-making ability is impaired because of a physical, mental, psychological or intellectual condition or state, whether or not the condition or state is a diagnosable illness.”

A guardian is appointed when the ACAT is satisfied that:

- a) “someone has impaired decision-making ability in relation to a matter relating to the person’s health or welfare; and
- b) while the person has the impaired decision-making ability—
 - i) there is, or is likely to be, a need for a decision in relation to the matter; or
 - ii) the person is likely to do something in relation to the matter that involves, or is likely to involve, unreasonable risk to the person’s health, welfare or property; and
- c) if a guardian is not appointed-
 - i) the person’s needs will not be met; or
 - ii) the person’s interests will be significantly adversely affected.”

Referring to a “condition” or disability as an aspect of capacity is a common but problematic approach in guardianship legislation. The reference refigures questions of capacity from being decision specific, and instead rests on interpretations of disability. This ignores the expectation under the CRPD that everyone is to be treated equally under the law, and has the right to freedom from discrimination on the grounds of disability. Certainly, the inclusion

of “condition” in the legislation rests on a discriminatory connection between particular disabilities and capacity.⁴²

Recommendation 4: Remove the medical approach to defining legal capacity from ACT guardianship legislation, including terms “condition” and “disability status.”⁴³

Most importantly, the legislation fails to recognise that decision making capacity exists on a continuum, and that all people, at different points and under different circumstances, make better or worse decisions. When a person needs support to make significant decisions over the course of their life, it is unlikely that they need this level of support for each and every decision in their life. Guardianship legislation does not account for this and removes the right for that individual to be responsible for any decisions in their life.

The legislation also overlooks the potential and the right for a person with ‘impaired decision making’ ability to build upon their decision making skills and to be supported to make decisions in a way that reduces risks and assists them to meet their needs. The legislation unnecessarily hinders capacity building in regards to decision making and creates a social and political environment that encourages people with disabilities to be dependent.

Further, it is certain that under current guardianship legislation and systems that rely on definitions of capacity more generally, people with disabilities are judged more harshly and are expected to demonstrate a decision making competency more consistently and forwardly than others in the community.⁴⁴ It could be argued that for many there is a presumption of incapacity and that they are required to prove otherwise. This contradicts all legal and human rights frameworks.

Current legislation places value on the quality of decision, rather than on decision making capacity alone. In recent amendments to the UK Mental Capacity Act 2005, the capacity to make a decision was not to be defined by the outcome of that decision.⁴⁵ If legislation is truly about recognising the capacity to make a decision, and people with disabilities are viewed as equal before the law, then the outcomes of decisions, or the existence of ‘poor’ decisions, cannot be considered indicative of an inability to make them.⁴⁶

Balancing the freedom to make ‘bad’ decisions and the right to be protected from vulnerability is complex. Current guardianship legislation does not accommodate this complexity. It was recognised by the Attorney General’s Department of New South Wales that legislation should recognise that “the right of a person to *rationaly make an unwise decision* should be as available to a person whose capacity is in question as it is to anyone else.”⁴⁷

Finally, only in the ACT and Queensland is not *communicating* a decision legally equivalent to not making one. These sorts of legal definitions of capacity are stagnant, and offer little room for a temporal or contextual approach to capacity.^{48 49}

Arguably, these legal definitions of incapacity do not always meaningfully reduce risks faced by people with disabilities, but serve the risk management needs of organisations and

⁴² Attorney Generals Department NSW, Op. Cit.

⁴³ Ibid.

⁴⁴ Chartres Op. Cit.

⁴⁵ Browning, M., 2010, *To Investigate New Models of Guardianship & the Emerging Practice of Supported Decision Making*, Winston Churchill Memorial Trust of Australia

⁴⁶ Ibid.

⁴⁷ Attorney Generals Department NSW, Op. Cit. p 17

⁴⁸ South Australian Office of the Public Advocate op. cit., Victorian Law Reform Commission Op. Cit.

⁴⁹ Advocacy for Inclusion, 2011, *Submission to ACAT Tribunal*,

<http://www.advocacyforinclusion.org/publications/Submissions/2011/submission%20to%20the%20acat%20afi%20adacas%20dec2011.pdf>

providers who will engage with the person under the guardianship order,⁵⁰ like banks, institutions and service providers.

Recommendation 5: The ACT and ACAT to develop appropriate mechanisms by which the finding of legal incapacity is limited to certain decisions, situations and timeframes, recognising decision making capacity as existing on a continuum.^{51 52 53}

Recommendation 6: In line with good practice models operating in the UK and Ontario and commended by the World Health Organisation, a definition of legal capacity should be outlined and legislatively transparent, measured by whether an individual:

- a) understands the information relevant to making a particular decision;
- b) uses and weighs that information as part of the decision-making process;
- c) appreciates the reasonably foreseeable consequences of the decision and of not making a decision;
- d) makes the decision voluntarily; and communicates the decision (whether through speech, writing, sign language or any other means), using the most appropriate communication form to that person.^{54 55}

Problems in Substitute Decision Making

The Act stipulates that a guardian should make decisions on behalf of a person that are “as nearly as possible, the decisions that he or she would have made if not affected by the condition concerned”. However, a UK study conducted amongst support workers in residential homecare found that decisions were typically made according to the personal valued goals of the supporter.⁵⁶ Similarly, our survey demonstrates that there are cases where people feel decisions are being made for them without consideration of their expressed wishes. It therefore is questionable that guardians are reasonably able to make decisions on behalf of a person without ultimately being influenced by their own personal interests, values and beliefs. Guardianship is inevitably laden with these conflicts of interest.⁵⁷

Guardianship orders necessitate an imbalance of power, unequal access to legal assistance and uneven valuing of knowledge in both procedure and outcome.⁵⁸ The perception that guardianship only protects and cares for people with disabilities is unrealistic and must be challenged; there are numerous and harrowing examples where this is not the case.⁵⁹ Certainly in related issues of forced sterilisation and medical treatment, the concept of ‘best interests’ has been used to serve the interests of the carer, to the appalling detriment of a person with disability.⁶⁰ Guardianship can be the very tool used against people with disabilities, who are all the more vulnerable when their voice is not legitimised.

⁵⁰Victorian Law Reform Commission, Op. Cit.

⁵¹ Ibid.

⁵² Bach, Op. Cit.

⁵³ International Guardianship Network, Op. Cit.

⁵⁴ Bach, Op. Cit.

⁵⁵ Ibid.

⁵⁶ Dunn, M. C. et. al., 2010, A Life Like Ours?, *Journal of Social Welfare and Family*. 54(2):144-160 – Interviews with support care workers in residential homecare found that in contrast to the narrow legal explanation of substitute decision making, decision makers made choices on behalf of their clients that actually reflected their own personal goals and values, attempting to see residents live ‘a life like ours’, rather than those of the supported person.

⁵⁷ Ibid.

⁵⁸ Victorian Office of the Public Advocate, 2009, *Supported Decision Making Background Discussion Paper*, Melbourne

⁵⁹ Chartres, Op. Cit.

⁶⁰ Dowse, L. and Frohmader, C. 2001, *Moving Forward: Sterilisation and Reproductive Health of Women and Girls with Disabilities*, Women with Disabilities Australia (WWDA), Tasmania, Australia.

With the prospect of unending guardianship arrangements, and limited ongoing education and support offered to guardians about the responsibilities of their role, there exists significant room for major rights infringements.

While national guardianship standards exist, which seek to encompass the regulations of Article 12,⁶¹ it is unlikely that standards can realistically address the power imbalance that guardianship, by its nature, imposes, most often out of public view.

In most jurisdictions across Australia, guardianship orders allow a guardian to act against the wishes of an individual, in the event that these wishes are deemed detrimental. In Queensland, the Tribunal noted that

“the guardianship regime is not simply a ‘substitute decision making regime’ but a regime that must act in the best interests of the adult, and as such, allows guardians to make decisions which may restrain or contain the person under guardianship could be help, diagnosed and treated against their stated views ...”⁶²

Accountability is a major issue with guardianship. The feedback we have received through our direct practice and the Guardianship Survey indicates a lack of systematic measures for transparency and accountability around how substitute decisions are made and the communications that inform them. Particularly where there are enduring or familial guardians, the relationship may never be opened up for appraisal – outside of a three yearly review by the Tribunal – if external appearances suggest decisions are being made ‘well’.

Few legal protections are afforded to carers or families operating under naturally developed informal frameworks if they do not have formal guardianship orders⁶³. Parents and families have expressed that their support role is not recognised by institutions, creating barriers for the person to access natural decision making supports. Because of this, the legal reliability afforded by a guardianship order means that there is an impetus and belief that one must seek plenary guardianship orders, regardless of whether they are necessary, for the day to day decision making process for that person.⁶⁴

Similarly, in our advocacy practice we have come across numerous cases where people feel a guardianship order is necessary because the focus person’s rights and wishes are ignored by institutions. Guardianship is seen as a measure to give weight to the person’s rights. Clearly, this is not a matter concerning a person’s decision making capacity; rather it is a cultural problem wherein people with disabilities are not being heard and a person without a disability is seen as the one with the legitimate voice. Guardianship practices create and compound this.

It is fair to say that a ‘culture of guardianship’ exists, brought about by long held protectionist beliefs about people with disabilities and incapacity, and a focus on risk management. It is encouraged by the absence of any other recognised decision support system to assist families and people with disabilities to negotiate models for when a person turns 18.

“I get the general impression that many service providers, especially in the medical field, assume that if a person has any cognitive limitation or even any disability they

⁶¹ Australian Guardianship and Administration Council, 2009, *National Standards of Public Guardianship*, http://www.agac.org.au/images/stories/national_stands_public_guardianship.pdf

⁶² O’Neill, N., & Peisah, C., 2011, *The Functions and Powers of Guardians, Capacity and the Law*, p 76

⁶³ Victorian Law Reform Commission, *Op. Cit.*

⁶⁴ Attorney Generals Department NSW, *Op. Cit.*

automatically need a guardian to make decisions for them. Often people think that the solution to a person's problems is getting them a guardian."⁶⁵

When partial orders are made in favour of plenary orders, it becomes likely that where substitute decision making is employed in regards to some aspects of an individual's life, it is gradually applied to more areas as a result of assumptions (both personal and public) of incapacity.⁶⁶ Indeed, even while legal 'supporter' models such as the Representative Agreements in British Columbia (discussed below),⁶⁷ may be seen as an improvement to plenary approaches, they still place the choice to opt for substitute decision making in the hands of the representative, creating space for the social implications of disability and capacity discourses to have effect.

Recommendation 7: ACAT to develop capacities for transparent and systematic review of standing guardianship arrangements, including allowing for an order to be rescinded.

Recommendation 8: Review accountability measures under guardianship orders, including transparency mechanisms for substitute decisions, and complaint processes for those under orders.⁶⁸

Figuring Guardianship with Human Rights

To meet Australia's obligations under the CRPD and *Universal Declaration of Human Rights*, substantial work will need to be done in regards to domestic disability legislation⁶⁹, including guardianship. As Chartres significantly concludes, our laws should enhance the application of human rights, not suppress them.⁷⁰ Our guardianship law does not currently achieve this.

Many are concerned that amending guardianship legislation would leave vulnerable members of the community at greater risk, and without support. It is pertinent for the ACT to consider better ways to address vulnerability that also meet human rights obligations⁷¹. One such example is in place in the UK and US in the form of adult protection legislation, which emphasises vulnerability, not decision making capacity in a 'whole of sector' response to protection. Beginning a discussion on adult protection legislation may deemphasise the role of decision making capacity in social concepts of safety.⁷²

Recommendation 9: The ACT to investigate the development of adult protection legislation, which may provide some of the safeguards currently considered necessary under guardianship without the appointment of a guardian.⁷³

Hungary based human rights organisation Mental Disability Advocacy Center (MDAC) has carried out some of the only work on figuring guardianship legislation to suit human rights principles. Their recommendations stress the right of appeal, limiting the rights of guardians (non-plenary orders), recognising the distinction between legal capacity and 'functional

⁶⁵ Advocacy for Inclusion survey respondent (disability advocate)

⁶⁶ Bach, Op. Cit.

⁶⁷ Representation Agreements are intended to act as Supported Decision Making agreements however they allow for the use of substitute decision making in the event that a decision cannot be made.

⁶⁸ International Guardianship Network, Op. Cit.

⁶⁹ People With Disabilities Australia, 2009, *Everyone, Everywhere: Recognition of Persons with Disability as Persons Before the Law*

⁷⁰ Chartres, Op. Cit.

⁷¹ Amnesty International, 2011, *Chapter 2- Capacity, Supported Decision Making, Advance Directives and Substitute Decision Making: the Right to Equal Recognition Before the Law- Legal Capacity*, Amnesty International Ireland

⁷² Brayley Op. Cit. – Adult protection places less emphasis on capacity and more on vulnerability, making adult protection the responsibility of intersecting and communicative agencies and representative bodies. This is an important step in recognising that vulnerability is not equivalent to incapacity, and that removing legal recognition of decisions is not a proportionate response to risk of abuse or neglect.

⁷³ Brayley, Op. Cit.

capacity⁷⁴; requirements for greater accountability of guardians and addressing the link between guardianship and institutionalisation.

The MDAC recommendations for human rights oriented guardianship framework is a useful place from which to begin reconsidering guardianship legislation.^{75 76} Many of these recommendations were also made by the Victorian Law Reform Commission in their 2012 report *Guardianship: Final Report*.⁷⁷

Recommendation 10: Reform guardianship processes to comply with human rights obligations under the CRPD.^{78 79}

Human rights oriented models such as Supported Decision Making (discussed below) do not deemphasise the necessity of decision making, but treat decision making capacity as existing on a continuum related to context and timing. That is, all people are seen as capable of making decisions, under certain conditions, and with certain individually considered supports. In this way, capacity does not need to be defined in the formal legal or medical sense, but rather, according to a person's expressed preference, and demonstrated understanding of options.^{80 81 82}

Recommendation 11: The ACT to amend guardianship legislation to promote the use of Supported Decision Making models⁸³ instead of appointing a substitute decision maker. The ACT to affirm decision making rights of the focus person and the role of supporters.⁸⁴ This should be done with a view towards facilitating the removal of legislation entirely in the longer-term future, replaced with Supported Decision Making models that function less formally in the community.

Under any system informed by a view of defining legal capacity, people with disabilities may be required to demonstrate a competency in decision making that other members of the population are not. When we consider legislation, we must develop an understanding that people with disabilities *will and can* make their own decisions, and that these decisions cannot be open to more scrutiny than those made by the general population.⁸⁵ Challenging these long held assumptions will be one of the most crucial and difficult parts of reviewing guardianship in the ACT.

Moving on from legal-capacity driven perspectives is a long term goal. Most immediately, the ACAT should make significant effort to transition away from plenary guardianship orders to a less restrictive, more specific concept of capacity. Over time the number of guardianship orders should reduce, with the long term goal being that guardianship is phased out for use only in very rare circumstances where alternatives have already been exhausted.

⁷⁴ Mental Disability Advocacy Center, *Analysis of Russian Legal Capacity System for Persons with Mental Disabilities: Towards Implementation of Article 12 of the UN CRPD*, <http://www.mdac.info/en/resources/analysis-russian-legal-capacity-system-persons-mental-disabilities-towards-implementation> - A person's functional capacity fluctuates across time, and is dependent on the type of decision being made.

⁷⁵ Carter, Op. Cit.

⁷⁶ Mental Disability Advocacy Center, Op. Cit.

⁷⁷ Victorian Law Reform Commission, Op. Cit.

⁷⁸ Carter, Op. Cit.

⁷⁹ Mental Disability Advocacy Center, Op. Cit.

⁸⁰ Robert M Gordon, 2000, *The Emergence of Assisted (Supported) Decision Making in the Canadian Law of Adult Guardianship and Substitute Decision Making*, *International Journal of Law and Psychiatry*, 23(1):61-77

⁸¹ Office of the Public Advocate Victoria, Op. Cit.

⁸² Gordon, Op. Cit. – Dignity of Risk is an established position in disability theory that considers less ideal outcomes as part of the process of self-determination, rather than an indication of inability. Allowing risk to be positive, will better prepare service providers for Supported Decision Making.

⁸³ Victorian Law Reform Commission, Op. Cit.

⁸⁴ Brayley, Op. Cit.

⁸⁵ Victorian Office of the Public Advocate, Op. Cit.

Recommendation 12: The ACT to develop a framework in legislation to restrict substitute decision making and the finding of legal incapacity as last resort option, only to be used for specific decisions and limited time frames when supported decision making options have been properly tried and exhausted.⁸⁶ As recommended in *Essential Principles: Irish Legal Capacity*, a framework should include the following expectations:

- e) The best efforts must have been made to communicate with the person about the decision, through all possible means including unconventional communication;**
- f) Every effort must have been made to understand the person's will and preferences;**
- g) If there is no existing support network for that person one should be developed if possible;**
- h) Every effort must have been made to provide information in a manner that the person can understand and all means of support (including advocacy) should have been provided in order to help the person make a decision.⁸⁷**

⁸⁶ *Essential Principles: Irish Legal Capacity Law*, 2012, http://www.nuigalway.ie/cdlp/documents/principles_web.pdf

⁸⁷ *Ibid.*

The transition towards Supported Decision Making

International human rights obligations towards people with disabilities under Article 12 of the CRPD place us in a better position to consider guardianship models critically.⁸⁸ Disability services, carers and lawmakers should be moving towards using models where people are supported to make their own major decisions, on a case by case basis, according to their support needs. This kind of flexibility is afforded by Supported Decision Making models.

What is it?

The current substitute decision making model in the ACT guardianship legislation differs greatly from Supported Decision Making. Supported Decision Making is a community based skills building model of support, which empowers people with cognitive disabilities to make and communicate decisions about their lives. Instead of assigning a substitute decision maker, the supported person retains their right to make decisions and is supported to exercise this right.

It is not counselling or therapy; it involves consultations where specific decisions are addressed, weighed, and concluded by an individual with support from others.⁸⁹ The support people are not professionals; they are general members of the community who are trusted and chosen by the focus person.⁹⁰

Most significantly, in this model decision making capacity is understood to exist on a continuum, where decision making skills can be built up, supported, suppressed, and differ across various contexts and circumstances.⁹¹ The model assumes that all people have preferences, wants and needs, which can be built into autonomous decisions when people are supported to do so. It recognises that “people with disabilities have histories and aims”⁹², which are expressed through the decisions they make.

Supported Decision Making acknowledges the role of social support in decision making by all people and that few people make decisions in isolation. Collaboration and relationship building to promote autonomy and self-advocacy are core values. In this way, Supported Decision Making reflects how most people make and weigh the choices in their life and differs from a substitute model wherein the capacity to make decisions is judged more critically for people with disabilities than others.⁹³

This model recognises that when a person makes a ‘bad’ decision, this does not mean that the person cannot make decisions altogether. Rather, it is appreciated that all people make ‘bad’ decisions from time to time and people with disabilities also have the right to make what might be considered ‘bad’ decisions. This is a natural and important part of life experience and learning. It may also indicate that a person needs different or additional support to make informed decisions.⁹⁴

⁸⁸ Bach, Op. Cit.

⁸⁹ South Australian Office of the Public Advocate, Op. Cit.

⁹⁰ Ibid.

⁹¹ Nicholson, C., 4 April 2012, *Decision making – South Australian Project*, Presentation, Dana Conference, Australian Capital Territory

⁹² The United Nations Handbook, *Chapter Six: From Provisions to Practice: Implementing the Convention*, <http://www.un.org/disabilities/default.asp?id=242>

⁹³ Victorian Law Reform Commission, Op. Cit.

⁹⁴ Attorney Generals Department NSW, Op. Cit.

Major principles of Supported Decision Making

- All people can and should be encouraged to make the decisions that will affect their lives.
- Control over choice, employment and circumstance are a fundamental aspect of meeting Article 12.⁹⁵
- All people have a right to decision making support if they wish to receive it.
- Everybody can communicate their preferences and will if supported to.
- People can develop the skills to turn preferences into decisions.
- 'Dignity of risk' - the right to take risks - is an aspect of social inclusion.
- All people make both good and bad decisions. We all learn from experience.
- Part of exercising the right of decision making, is being responsible for these decisions.
- "Competency can be learned, influenced, enhanced and suppressed."⁹⁶
- Decision making is a social and personal skill that can be taught and learnt.⁹⁷

Why should we have it?

Decision making shapes our histories and futures; it is fundamental to our self-expression, our personhood and our quality of life. We all expect control and autonomy over our lives and decisions. As a community, we must recognise that these expectations do, and must also exist for people with disabilities.⁹⁸ The denial of a person's access to decision making rights should never be taken lightly.

Substitute decision making is becoming widely recognised as an out dated practice,^{99 100 101} with the emphasis shifting from people with disabilities as passive service recipients to supporting them to be active members of the community¹⁰². These changes are natural social progressions as people with disabilities become more included in society and can only continue with corresponding legislative changes. Supported Decision Making models align well with this and are an essential part in these progressions.

Moving toward Supported Decision Making is a necessary transition in any human rights approach to disability. The United Nations *Convention on the Rights of Persons with Disabilities* has been the driving force behind moves towards Supported Decision Making around the world. The right to decision making autonomy, and the importance of Supported Decision Making, is mentioned specifically in the Convention's General Principles.

"Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons"

and in Article 12 (3):

"State Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."¹⁰³

It is also explicitly referred to in the United Nations' *Concluding Observations* for Spain 2011 and Tunisia 2011¹⁰⁴, giving great clarity to how the United Nations interprets the Convention:

⁹⁵ Victorian Office of the Public Advocate, Op. Cit.

⁹⁶ Ibid. p 9

⁹⁷ Ibid. p 9

⁹⁸ Gordon, Op. Cit.

⁹⁹ *Essential Principles: Irish Legal Capacity Law*, Op. Cit.

¹⁰⁰ Inclusion Europe, 2008, *Key Elements of a System for Supported Decision Making*

¹⁰¹ Victorian Law Reform Commission, Op. Cit.

¹⁰² Ibid.

¹⁰³ United Nations General Assembly, 13 December 2006, *Convention on the Rights of Persons with Disabilities*

“The Committee is further concerned that no measures have been taken to replace substitute decision-making by supported decision-making in the exercise of legal capacity.¹⁰⁵

Recommendation 34: The Committee recommends that the State party review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person’s autonomy, will and preferences. It further recommends that training be provided on the issue to all relevant public officials and other stakeholders.”¹⁰⁶

Two major turning points in Australia came with the Productivity Commission Inquiry Report into *Disability Care and Support* and the development of the *National Disability Strategy* (NDS). A fundamental finding of the Productivity Commission’s report was that self-direction and choice are necessary parts of a person-centred and productive disability services model.¹⁰⁷ It highlighted the need to include provisions for self-directed funding and Supported Decision Making.¹⁰⁸ Self-directed funding models rely on the ability of people with disabilities to make their own decisions in order to achieve the positive health and mental health outcomes that are attributed to the introduction of such a scheme.

Similarly, the *National Disability Strategy*¹⁰⁹ echoes the need to implement human rights initiatives and person centred approaches across a range of areas within disability services to support people with disabilities to enjoy equal citizenship. The *National Disability Strategy* focuses on key areas such as inclusivity, justice and rights protection, personal and community support and skills and learning. Supported Decision Making is in line with these initiatives, and encourages broader justice and rights improvements that meet NDS aims.

With the NDIS set to roll out in 2013,¹¹⁰ state governments will need to instigate significant changes to the way that disability services are run and understood. To attain the maximum benefit from an NDIS, the ACT Government needs to ensure that provisions for Supported Decision Making exist in relevant legislation and that people with disabilities and their support networks are equipped with the skills to make this a reality.¹¹¹

All people benefit when their decisions and preferences are meaningfully recognised.¹¹² Supported Decision Making, in combination with the NDIS offers the potential for people with cognitive disabilities to have greater control over their budgets, needs, preferences and interactions with others.¹¹³ For some, the NDIS might be the first time in their lives when their choices have been out of the hands of service providers. Supported Decision Making is a necessary aspect of skill development in a changing service environment.

Supported Decision Making models allow people the opportunity to articulate their aims, identify, manage and obtain supports to address these aims, and enjoy control over their

¹⁰⁴ United Nations, April 2011, *Committee on the Rights of Persons with Disabilities: Fifth Session*

¹⁰⁵ United Nations, September 2011, *Committee on the Rights of Persons with Disabilities: Sixth Session*

¹⁰⁶ Ibid.

¹⁰⁷ Productivity Commission, 2011, *Disability Care and Support*, Report 54 (1), Commonwealth of Australia

¹⁰⁸ Productivity Commission Op. Cit.

¹⁰⁹ National Disability Strategy, Op. Cit.

¹¹⁰ Advocacy for Inclusion, 2011, *Submission to Act Budget Consultation 2012-13*,

<http://www.advocacyforinclusion.org/publications/Submissions/2012/advocacy%20for%20inclusion%20submission%20to%20act%20budget%20201213%20final.pdf>

¹¹¹ Ibid.

¹¹² Australian Social Inclusion Board, Op. Cit.

¹¹³ Council of Australian Governments, 2012, *Progress Report: Building a National Disability Insurance Scheme*, http://www.coag.gov.au/coag_meeting_outcomes/2012-04-13/docs/NDIS_progress_report.pdf

resources that too many have been unnecessarily and bluntly denied.¹¹⁴ This is likely to contribute to better service outcomes and broaden community attitudes and aspirations as service drivers for consumers, developing a pro-inclusion and pro-rights stance among agencies.¹¹⁵

¹¹⁴ Gordon, Op. Cit.
¹¹⁵ Chartres, Op. Cit.

What might Supported Decision Making look like in the ACT?

Supported Decision Making is a relatively new approach to supporting people with disabilities, particularly in Australia, meaning that approaches, risk management mechanisms and legal boundaries are still being defined. South Australia is currently conducting the first trial of Supported Decision Making in Australia, and it is likely that Victoria will respond to the Victorian Law Reform Commission recommendations to do the same.

National and international examples that could inform models in the ACT are discussed below. In light of these examples and the general motivational push towards Supported Decision Making across the world, it is an opportune time to develop a trial in the ACT. It is likely that a Supported Decision Making model in the ACT will work differently to other States - the significance is in acknowledging that we must move forward.¹¹⁶ Models should be flexible and adaptable to individual needs and wishes.

Some Supported Decision Making mechanisms are less formal than others, meaning that there is room to initially trial Supported Decision Making arrangements and training in ways that would not require extensive adjustment of current legislation in the ACT. For those to whom Supported Decision Making appears a radical approach, a trial will allow them to ease into the concepts and develop trust in the model by demonstrated outcomes. Supported Decision Making appears most successful when employed in the instance of caring, trusting and long established relationships.^{117 118} It is for this reason that the community sector, or advocacy agencies, would be best positioned to guide trials, and to whom less legislatively complex models may be more suitable.

While government must be supportive by providing services, funding and community scope, Supported Decision Making is an activity for the community, not the government.¹¹⁹ The community sector will also be integral to challenging stereotypes and distributing information necessary to promote a Supported Decision Making trial. Partnerships between the independent community sector and government agencies will be essential to ensure responsibility, independence and access.

Recommendation 13: The ACT to resource a community organisation to undertake a researched trial of Supported Decision Making in the ACT, building upon, but not replicating, the South Australian pilot.

Recommendation 14: The ACT to ensure legal professionals, government officials, the Public Advocate and ACAT are fully trained in Supported Decision Making and obligations under the CRPD.

Recommendation 15: The ACT to resource the community sector to train people with disabilities and their supporters on using Supported Decision Making successfully.

Current models

Canada: Parts of Canada offer the most comprehensive examples of effectiveness of Supported Decision Making. Canada is one of the few jurisdictions operating several models of Supported Decision Making. It has been labelled the 'best practice' model in the eyes of the United Nations. British Columbia has pioneered representation agreements - statutory

¹¹⁶ Chartres, Op. Cit.

¹¹⁷ Browning, M. Op. Cit.

¹¹⁸ Victorian Law Reform Commission, Op. Cit.

¹¹⁹ South Australian Office of the Public Advocate, Op. Cit.

arrangements which formalise Supported Decision Making in a recognised agreement which can also be used to make substitute decisions. These agreements are made and directed by individuals needing support - an important point of difference to guardianship.¹²⁰ Both participants in an agreement face legal obligation. Proving or disproving capacity does not form part of the agreement making process. Rather, emphasis is placed on proving a trustful relationship exists. Laws are applied to the population equally, so 'disability status' does not mean people are subjected to agreements or 'review' under the legislation.¹²¹

In Edmonton and Calgary, a variety of decision making models exist (many of these were recommended by the Victorian Law Reform Commission) including co-decision making, Supported Decision Making and substitute decision making, all recognising presumed capacity and respect for individual autonomy.¹²² However, the legal role of supporters is not as clearly identified in these models as in British Columbia.

United Kingdom: England has adopted the *Mental Capacity Act 2005* which is a statutory framework on capacity and decision making. The framework makes some substantial achievements in recognising the social model of disability and the importance of human rights to disability services. The starting point of the legislation is a presumption of capacity, and the legislation specifies that individuals must be given support to maximise their decision making autonomy. A person cannot be found to be incapable of making autonomous decisions until all practical steps have been undertaken to demonstrate this.

Significantly, making unwise or 'bad' decisions is not considered indicative of an inability to make decisions - a principle of Supported Decision Making. Capacity assessments are made by individuals directly involved with a person at the time a decision must be made. This emphasis on decision making timing is in contrast with fixed views of capacity, especially given that the Act recognises that communication and timing are integral to decision making competency.¹²³

While the possibility for conflict of interest exists in regards to the decision specific involvement of others (i.e. if individuals calling for the capacity assessment are involved in the outcome of a decision), recognising the flexible nature of capacity is a ground breaking development. Further, concern has been raised that substitute decision making that is reliant on decision specifics allows for insufficient protection for people who need substantial support in complex manners. There is evidence that vulnerable people have been left without protection under the new legislation.¹²⁴

South Australia: The South Australian trial model is a non-statutory trial where no legislative recognition is given to the arrangement, but where the supported person appoints a supporter, rather than a tribunal appointing a guardian. The model reflects human rights obligations by not allowing for substitute decision making, though a monitor has overseen decision making processes. The monitor acts to support both parties in the agreement and provide a safety net should the arrangement break down. This trial is under the auspice of the Office of the Public Advocate in South Australia.

Based on these examples, potential models for the ACT are discussed below. In all models discussed, supporter relationships should be trust based; abuse would be met with legal consequence, and though supporters would not be liable for decisions, they should be held accountable where they demonstrate negligence, criminality or failure to comply with

¹²⁰ South Australian Office of the Public Advocate, Op. Cit.

¹²¹ Browning, Op. Cit.

¹²² Browning, Op. Cit.

¹²³ Victorian Office of the Public Advocate, Op. Cit.

¹²⁴ Browning, Op. Cit.

obligations.¹²⁵ It is in this regard that investigating broader adult protection legislation (as discussed earlier) is of some significance.

Circle of support, network Supported Decision Making: non statutory

What it is: Circles of friends, or circles of support, offer group input and decision making support within a structured setting. Circles of support act as a community around a person to help them achieve their goals and settle on decisions and choices. Circles have been adopted in a variety of social support contexts, and operate on the principle that ‘more hats’ can offer more ideas and accountability. Indeed, most of us seek the advice of a few others when it comes to making important life choices. Ideally, circles of support would comprise of trusted friends who would volunteer their time to participate in the circle. Where trusted others could not be found, it would be possible to train volunteers to act in the circle.

Typically, circles work well when supporters with a wide range of interests or areas of expertise act together to support decision making. Circles would operate informally (or perhaps semi-formally if an agreement had been made with a single supporter who acted with the group). The agenda of meetings and participants are decided by the ‘focus person’, meaning that circles of support act as highly beneficial tools for facilitating autonomy, self-advocacy and skill development.¹²⁶ Presumably, circles could operate on a need-for-decision basis, or on a more regular basis to build trust, communication and familiarity. Depending on circumstance, a facilitator may work with the group, though focus and outcome is up to the focus person’s discretion.

Where it is currently practiced: MDAC,¹²⁷ United Kingdom – “The Circles Network.”¹²⁸ South Australia - Community Living Project.¹²⁹ New South Wales – Resourcing, Families,¹³⁰ Toronto (informal).¹³¹

Positives:

- Diversity of influence and support for decision making with more people involved.
- Greater accountability and safeguarding against coercion or substitute decision making.
- Variety of support when people have different strengths, this is a more realistic reflection of decision making and social communication in the general community.
- Less need for a formal monitor (relevant to budget considerations).
- It is a long term arrangement that can be used as and when major decisions arise.
- Circles improve social inclusion and communication skills.
- There is potential for supported people to develop their own decision making skills and act as a part of other circles, much like the Peer Network Advocacy for Inclusion currently operates.¹³²
- A non-statutory agreement may best reflect the reality for some family or friendship circles already operating Supported Decision Making informally or under guardianship.
- For people who do not have trusted others, a network could be put together using volunteers.¹³³

¹²⁵ Victorian Law Reform Commission, Op. Cit.

¹²⁶ Gee, A., *Circles of Support for People with Disability*

<http://www.assid.org.au/Portals/0/Conferences/NZ2010/Circles%20of%20Support%20for%20People%20with%20Disability%20-%20Ainslie%20Gee.pdf>, The Australasian Society for Intellectual Disability

¹²⁷ Mental Disability Advocacy Center, Op. Cit.

¹²⁸ Circles Network, *Circles of Support*, http://www.circlesnetwork.org.uk/index.asp?slevel=0z114z115&parent_id=115

¹²⁹ Community Living Project, Op. Cit.

¹³⁰ Resourcing Families, <http://www.resourcingfamilies.org.au/>,

¹³¹ Browning, Op. Cit.

¹³² Advocacy for Inclusion

http://www.advocacyforinclusion.org/index.php?option=com_content&view=category&layout=blog&id=4&Itemid=6

Considerations:

- In the South Australian trial it was often difficult to find more than one trusted other for people seeking support.
- Finding enough volunteers to form an operative circle may not always be possible.
- Greater requirements for all members of circle to be trained.
- The dynamics of group communication may not suit all.
- Semi-formal measures may need to be developed to have the arrangement recognised by institutions.
- Less capacity for official reviews, safeguarding, monitoring and accountability processes in a non-statutory model.

Recommendation 16: The ACT to facilitate the development of non-statutory circle and peer network Supported Decision Making models in the community by funding community agencies to develop these models.

Single Supported Decision Making arrangements: non-statutory

What it is: A non-statutory Supported Decision Making arrangement would operate with more flexibility than a statutory model. Non-statutory relationships would operate under agreement by both parties and could be ended at any time. The appointment of a supporter would be entirely a supported person's own choice. The person receiving support would outline the decisions they need support with, and recognise that the responsibility for decisions is their own. The supporter would respect the decisions, preferences and personality of the person they are supporting, and recognise their role as a supporter, not substitute decision maker. As an informal arrangement, the supported person is under no obligation to use the agreement.¹³⁴

Where it is currently practiced: South Australian trial,¹³⁵ recommended by the Victorian Law Reform Commission,¹³⁶ United Kingdom (in principle - afforded by the *Mental Capacity Act 2005*).¹³⁷

Positives:

- Single trusted others may be easier to find, than participants for a network model.
- Allows for the building of a supported relationship and closeness with supporter.
- Non-statutory model would allow greater flexibility however research would need to review commitment to the arrangements and whether individuals are getting appropriate support without regulations in place.
- Would allow those arrangements that already operate in such a way to avoid unnecessary legal verification.¹³⁸
- Can be monitored by independent body.
- Supported person is not obliged to use agreement.¹³⁹

Considerations:

- Single supporter leaves greater room for violations, coercion and substitute decision making.
- Less capacity for official reviews, safeguarding, monitoring and accountability processes in a non-statutory model.

¹³³ Victorian Law Reform Commission, Op. Cit.

¹³⁴ South Australian Office of the Public Advocate, Op. Cit.

¹³⁵ Ibid.

¹³⁶ Victorian Law Reform Commission, Op. Cit.

¹³⁷ Browning, Op. Cit.

¹³⁸ Victorian Law Reform Commission, Op. Cit.

¹³⁹ South Australian Office of the Public Advocate, Op. Cit.

- Semi-formal measures may need to be developed to have the arrangement recognised by institutions.
- Informality might lead to substitute decisions, particularly where invested supporters feel they act in ‘best interest’.

In any non-statutory Supported Decision Making model accountability and official review process is of concern.

Recommendation 17: Government and agencies to develop appropriate safeguards for any formal Supported Decision Making trial.

Transitional Models

Reform should and will be a continual evolution; moving towards models such as those above will not happen overnight as it demands significant change in systems and practices. A transitional period will be necessary to develop community trust and skills in Supported Decision Making mechanisms, including the development of training and networks.

In recognition of this, statutory Supported Decision Making models, representation agreements and co-decision making agreements are discussed as potential statutory frameworks which may begin this process of transition.

These transitional models will not result in full implementation of Article 12 of the CRPD. Rather, they will facilitate a progression towards full implementation. When considering these transitional models, this must be in light of which will best reflect obligations under the CRPD. Considerations must include which model will best encourage the adoption of Supported Decision Making, which will facilitate transition best, which works best to shape attitudes about the capacity for people with cognitive disabilities to be decision makers, and which will avoid automatic and quick rejection from governments, support workers and associated institutions.

Representation agreements

What it is: Representation Agreements are essentially Supported Decision Making models however they allow for substitute decision making in instances where Supported Decision Making is deemed to be ineffective, and decisions need to be made.¹⁴⁰ Importantly, while Representation Agreements do allow for substitute decision making, they differ significantly to guardianship in that substitute decision making is employed on a decision specific basis, recognising a continuum of capacity. Representation Agreements do not require a test for capacity, and presume capacity for everyone. Representation Agreements require individuals to express their desire for an arrangement, demonstrate preferences and choices and provide evidence of a trusting relationship, in order for an Agreement to be recognised.¹⁴¹

Where it is currently practiced: British Columbia and Alberta, Canada

Positives:

- Promotes the use of Supported Decision Making as first preference over substitute decision making.
- As it does not entirely remove the use of substitute decision making it may be the most comfortable model for community members to prepare for a full transition into supported decision making models.

¹⁴⁰ Brayley, Op. Cit.

¹⁴¹ Ibid.

Considerations:

- Involves substitute decision making and so does not fulfil human rights obligations.

Statutory Supported Decision Making agreements – single and circles of support

What it is: Like an informal agreement, a statutory Supported Decision Making agreement would place a supporter, or supporters, and supported person together for the purpose of supporting the focus person to make decisions in specific areas of their life. A statutory agreement would be recognised by the Tribunal, and would afford status to supporters and legal recognition of the agreement. Recognising relationships in a statutory way would allow for greater monitoring and safeguarding. Unlike a non- statutory agreement, the supported person and the supporters could not ignore the agreement if it were not suiting them as it would have to be legally altered via the Tribunal. The supported person is obliged to seek support and the supporters are obliged to provide support for specific decision making matters; however the focus person retains final decision making responsibility.

Where it is currently practiced: British Columbia (as an aspect of a representation agreement), Alberta, (aspect of representation agreements), United Kingdom (afforded in principle through the *Mental Capacity ACT 2005*), recommended by the Victorian Law Reform Commission.

Positives:

- It does not involve substitute decision making and promotes the decision making rights of the focus person, which is more in line with the CRPD.
- It could be used as a progression from representation agreements if moving straight into a Supported Decision Making model is deemed too radical.

Considerations:

- A circle of support model may be more transparent and reduce risks of violations, coercion and substitute decision making compared with a single supporter model.
- It is less flexible than a non-statutory agreement and would require a formal process to remove or change the arrangement.
- South Australia recognised that formalising friendships could be an awkward process.¹⁴² This may impinge on organic relationships and processes.

Co-Decision making agreements

What it is: Co-Decision making enables people who need decision making support to enter into agreements with a co-decision maker. The co-decision making agreement requires decisions to be made in collaboration with assistance from a trusted other. In a co-decision making arrangement, both parties have legal responsibility for a decision in partnership, and neither party can make a legally binding decision alone. In this sense, co-decision models are far more restrictive than supporter models, though do not equate to substitute decision making as both parties must agree to a decision for it to be valid.^{143 144} Co-decision making agreements have been recommended by the Victorian Law Reform Commission,¹⁴⁵ and are active in Alberta and Saskatchewan, Canada.¹⁴⁶

From a human rights perspective, co-capacity cannot be considered as meeting Article 12.

¹⁴² South Australian Office of the Public Advocate, Op. Cit.

¹⁴³ Victorian Law reform Commission Op. Cit.

¹⁴⁴ South Australian Office of the Public Advocate, Op. Cit.

¹⁴⁵ Victorian Law Reform Commission, Op. Cit.

¹⁴⁶ Ibid.

Where it is currently practiced: Alberta and Saskatchewan, Canada.

Positives:

- It recognises the focus person as a legitimate decision maker and does not involve substitute decision making.

Considerations:

- It is least in line with the CRPD out of the three transitional models as it effectively does not promote the person as having legal capacity in their own right.
- Liability is particularly complex in a co-decision model.

Barriers to implementing Supported Decision Making and obligations under the CRPD

Moving to a full implementation of Supported Decision Making will require a transition. Significant barriers - both social and legal - currently prevent Supported Decision Making from operating the way it must if it is to fulfil our obligations under the CRPD. It is only in acknowledging and addressing these barriers that we may introduce a model of decision making that sees people with disabilities achieve the autonomy that is their right. Advocacy agencies will be a large part of this process; however, governments, legislators, service providers and carers will all need to approach Supported Decision Making with open minds and proactive attitudes to bring Supported Decision Making to realisation.

Theoretical and legal

The most immediate issue facing proponents of Supported Decision Making models is the lack of supporting empirical evidence. While Canada has pioneered aspects of Supported Decision Making, and the United Nations has clearly outlined the expectation it is included in legislation, it is still a relatively new concept in regards to disability services. On a small scale, we know that Supported Decision Making works. Informally, Supported Decision Making is a reality.¹⁴⁷ The findings of the Victorian Law Reform Commission and South Australian Public Advocate demonstrate that this is the direction we should be moving.^{148 149}

However, while some real-world examples exist, demonstrating the workability and necessity of Supported Decision Making is difficult. Supported Decision Making invites a new complexity to guardianship laws. This complexity breeds uncertainty about whether adequate protections will exist.^{150 151} Certainly, in preliminary discussions within the community, vulnerability was consistently expressed as a concern.¹⁵²

Guardianship legislation is intended to protect people from being liable for decisions which it would be unjust or exploitative to hold them legally responsible for.¹⁵³ Certainly, a person should not be held liable for decisions if they should not reasonably be expected to do so in a given circumstance or without the right support. However, guardianship is wide open to abuse and realistically can be the very instrument used against vulnerable people to prevent them from having meaningful control over their lives.

One of the positive aspects of guardianship law is in holding people, third parties and institutions responsible for protecting vulnerable people against exploitation. Mechanisms for protection are necessary under Article 16 of the CRPD. Legislation must promote genuine protection of vulnerable people, however this is not achieved in its true sense by removing a person's legal capacity and denying decision making rights.

A defining and progressive aspect of the *Mental Capacity Act* in the UK is recognition that 'bad' decisions are part of decision making for everyone, and that we cannot conclude that bad decisions are indicative of an inability to make decisions.¹⁵⁴ UK legislation instead recognises that an integral part of protecting vulnerable people is supporting them to be a part of the process, and that concerns of vulnerability must always be balanced with ways in which people can be empowered to participate and remove themselves from isolation.

¹⁴⁷ Victorian Law Reform Commission, Op. Cit.

¹⁴⁸ Ibid.

¹⁴⁹ South Australian Office of the Public Advocate, Op. Cit.

¹⁵⁰ Victorian Law Reform Commission, Op. Cit.

¹⁵¹ Dunn et. al., Op. Cit.

¹⁵² Rea, K., 2012, *Supported Decision Making: Summary of Workshops*, ADACAS

¹⁵³ South Australian Office of the Public Advocate, Op. Cit.

¹⁵⁴ Victorian Office of the Public Advocate, Op. Cit.

Ultimately, we must recognise that with any model, (including, and demonstrated by guardianship), risks of violation exist. Supported Decision Making is not akin to denying people protection. Supported Decision Making seeks to remedy these tensions by affording protections from 'going it alone' when it comes to decision making, without denying the option of making decisions at all. In this way, Supported Decision Making models offer a balance that plenary guardianship cannot. Of course, these tensions are real and warranted, and will and should be negotiated by testing and trialling models to best find this balance. As the Public Advocate of South Australia has recognised, balancing freedom and protection will always cause debate - but this debate is not reason to avoid change.¹⁵⁵ It is all the more reason we need reformed legislation that realistically responds to these grey areas.

The relative newness of Supported Decision Making models must be embraced as an opportunity for Australia and the ACT to pioneer the next steps in social inclusion for people with disabilities.

Attitudes

To some, Supported Decision Making models may seem like a radical shift in the way that disability support is implemented. It will challenge long held perceptions and attitudes about people with disabilities and their capacity. Addressing government, community sector, social and political attitudes will be crucial to the success of Supported Decision Making.

Implementing Supported Decision Making models and moving towards a community that is more inclusive for people with disabilities necessitates attitudinal change. Attitudinal change is complex to measure and manage.¹⁵⁶ It is integral that attention is paid to this aspect of implementing human rights approaches, such as Supported Decision Making and the NDIS, so that they will have their intended impact. Without change to assumptions, beliefs and structures currently surrounding disability, these reforms could fall short of their potential.¹⁵⁷

The experience of greater inclusion brought about by Supported Decision Making will affect life experiences of people with disabilities as much as the major changes with service providers and other authorities mooted by the NDIS.¹⁵⁸

In our preliminary survey, group discussions and research,¹⁵⁹ significant attitudinal barriers to implementing Supported Decision Making in the ACT became clear.¹⁶⁰ Amongst carers, guardians, service providers and support workers there are significant concerns about safeguarding, regulating and insuring models of Supported Decision Making, as well as in many cases, deeply held beliefs that substitute decision making is most often the only operational model for people with disabilities. When talking of decision making competency, it is often those closest to people with disabilities who cite the need for enduring guardianship arrangements. It can be very difficult to conceive that an order is unnecessary

¹⁵⁵ South Australian Office of the Public Advocate, Op Cit.

¹⁵⁶ Kleeman, J. & Wilson, E., 2007, *Seeing is Believing: Changing Attitudes to Disability. A Review of Disability Awareness Programs in Victoria and Ways to Progress Outcome Measurement for Attitude Change*, Melbourne: Scope, <http://www.scopevic.org.au/index.php/cms/frontend/resource/id/125>

¹⁵⁷ O'Brien, Op. Cit.

¹⁵⁸ Thompson, et. al. Op. Cit.

¹⁵⁹ Yazbeck, M., McVilly, K., & Parmenter, T. R., 2004, Attitudes Toward People with Intellectual Disabilities, *Journal of Disability Policy Studies*, 15(2):97-111, Occasional Paper No. 39

¹⁶⁰ Ibid. – In terms of the current picture, Yazbeck found that “disability phobia” remains a part of Australian society and that there exist vast differences in what a ‘good attitude’ towards disability is amongst persons with a disability and persons without a disability. That is, people without disabilities consider good attitudes to mean “nice” and “helpful”. This finding may have some implications when working towards changing attitudes towards guardianship and substitute decision making- especially where guardians are seen as ‘well intentioned’.

given that legislation is seen as ‘protecting’ people,¹⁶¹ where people with disabilities face presumptions of dependency, vulnerability and intellectual incapacity.

Many of these concerns will only be addressed when we can gather qualitative and quantitative evidence of the strength of Supported Decision Making outcomes. Others can be assisted by adequate training and educative programs that prepare the community for person-centred models.

Improving community and individual attitudes has often been considered a function of community and individual ‘exposure’ or interaction with people on whom discriminatory attitudes or stereotypes are placed.^{162 163} However, it is likely that ‘exposure’ alone cannot produce attitudinal shifts.¹⁶⁴ Studies have found that it is in interaction over the long term on equal grounds that attitudinal change is most prominent.¹⁶⁵ This is of great significance to Supported Decision Making, as it does not only improve an individual’s access to autonomy and choice, but also contributes to the wider development of social inclusion even amongst those who have worked in long and consistent relationships with people with disabilities.

In this regard, while legislative and policy changes can impact the way in which the community responds to marginalised citizens, attitudinal change is a two way street – better attitudes demand better institutions and better institutions encourage better attitudes. It requires a tactical and collaborative effort to bring these separate indicators into play. Jurisdictions will address community attitudes and disinclination towards Supported Decision Making in different ways.

In British Columbia NIDUS/RARC act as the major promoter of Representation Agreements. They provide information, resources and referrals for people who may wish to set up a Representation Agreement. The organisation does a lot of work in promoting Representation Agreements and Supported Decision Making. Arguably, the disability movement is more advanced in Canada and so representative bodies face fewer barriers when negotiating with business, community and government about the rights of people with disabilities.¹⁶⁶

Similarly, In Vancouver, the Community Living Project aims to educate people on the principles of Supported Decision Making. The focus is on ensuring that the values of Supported Decision Making (the right to make a decision, dignity of risk, skill building and valuing the individuals’ talents and gifts) are respected. This is to ensure that those using Representation Agreements do not simply employ substitute decision making, but rather value the potential of the Agreement that they have made.¹⁶⁷

Research and advocacy practice suggest that programs to address attitudinal barriers and build a community and familial environment that recognises the value of Supported Decision Making will be integral to implement Supported Decision Making legislation. Non-government advocacy and other organisations are both the best situated, and most skilled in performing this community level work.

This work will include educational information on why the legislation has changed, self-advocacy and supporting self-advocacy training¹⁶⁸, Supported Decision Making values training and the role of supporters, guardians and family in Supported Decision Making models. It is likely that some work will also need to be done to mediate situations where a

¹⁶¹ Ibid.

¹⁶² Kleeman, Op. Cit.

¹⁶³ Thompson, et. al. Op. Cit.

¹⁶⁴ Ibid.

¹⁶⁵ Kleeman, Op. Cit.

¹⁶⁶ Browning, Op. Cit.

¹⁶⁷ Ibid

¹⁶⁸ Advocacy for Inclusion, Op. Cit.

person seeks the guidance of a supporter who is not in their immediate or current circle of support.¹⁶⁹ Finally, there will be an important role for advocacy agencies in supporting people to self-advocate, negotiate and build skills within Supported Decision Making agreements.

Bringing along the community sector

Experience in Canada has not only demonstrated the need for cultural change to support legislation for Supported Decision Making,¹⁷⁰ it has also demonstrated the need to ensure medical, legal and service professionals are informed of their roles under new models, so that their practice complements processes, rather than hinders them. In instances where these sectors have hindered the development of effective Supported Decision Making programs, the public advocate has played an important role in educating and negotiating outcomes. Similarly advocacy organisations will remain in the best position to fill an educational role in the ACT.

Parts of the community sector may have a way to go when it comes to recognising the need for Supported Decision Making. Given that service providers, support workers, and carers have such an impact on an individual's life experience, it is necessary that preparatory and educative campaigns are also targeted at this area. Without support from the community sector, and training which develops ways to implement this support in practice, Supported Decision Making will not interact well with service providers. The Victorian Law Reform Commission notes that often the challenge is in turning 'in principle support' for Supported Decision Making into practical changes to behaviour and provisions.¹⁷¹

It should be noted that in other jurisdictions legislative change does not always equate to cultural change.¹⁷² It will be necessary to consult widely with stakeholders, support workers, families, medical professionals and legal teams when beginning the process of introducing Supported Decision Making. Any legislative change and any Supported Decision Making trials will require parallel programs aimed at fostering the development of community and sector support.

Like the Community Living Project in Vancouver,¹⁷³ work should focus on the values, interests, talents and gifts of people with disabilities, to challenge common-held assumptions about best interest and incapacity which leads to the reliance on substitute decision making.

Recommendation 18: The ACT to fund the development of a program for families and supporters who may be involved in Supported Decision Making agreements. Like the Canadian Community Living Project, the emphasis should be on valuing skills, talents and interests. This should be co-designed with people with disabilities.¹⁷⁴

Recommendation 19: Government in collaboration with community sector and consumers to produce a campaign on educating the public on the rights and abilities of people with disabilities, in line with the most successful extended campaign for mental illness awareness Like Minds, Like Mine in New Zealand. This should be co-designed with people with disabilities.¹⁷⁵

¹⁶⁹ Nicholson, Op. Cit.

¹⁷⁰ Browning, Op. Cit.

¹⁷¹ Victorian Law Reform Commission, Op. Cit.

¹⁷² Browning, Op. Cit.

¹⁷³ Community Living Project, Op. Cit.

¹⁷⁴ Ibid.

¹⁷⁵ The New Zealand Ministry of Health Op. Cit.

Recommendation 20: Disability Inclusion and Awareness Training to be mandatory for people working in the disability sector.¹⁷⁶

Recommendation 21: The ACT to develop a program to track improvements or changes in community attitudes towards people with disabilities, which is undertaken consistently over the long term.

Recommendation 22: The ACT to fund resources for community organisations to distribute to workplaces, health service providers, housing providers, legal service providers and the general public. Resources should outline what Supported Decision Making is, how it works, why it is being explored and how to support it. These must include plain English pamphlets about Supported Decision Making. These materials should link to organisations running or facilitating training and Supported Decision Making.

Government

A major barrier evident in the 2012 budgets at Federal and Territory levels was that government disability initiatives do not take into account the way different sectors of the community are at times in opposing positions. Differing views on the necessity of guardianship exist within the disability sector, and distinctions between stakeholder's focus areas, models of disability and funding needs are hugely significant to how they will weigh and understand issues such as Supported Decision Making and the NDIS. These varying needs will mean that all parts of the disability sector will need to be consulted on guardianship reform.

It is integral that governments recognise the nuanced nature of any community sector, particularly disability. In the lead up to the NDIS, it is important that carers and service sector organisations do not become the sole voices of the disability sector, leaving people with disabilities and their representative organisations outside of these significant national debates.

The National Disability Insurance Scheme

The implementation of the NDIS will be a significant time of change in disability services. The NDIS acts as both an opportunity to address longstanding and problematic aspects of disability services and to implement new and innovative approaches. However, without recognising that the sector and people with disabilities need adequate preparations to move over to the NDIS, the ACT will fail to fully capitalise on this major opportunity.

The NDIS cannot be treated as a 'fix all' for issues within disability services. Individualised funding alone will not resolve issues of autonomy or human rights infringements¹⁷⁷. The importance and necessity of undertaking a variety of preparations (not just economic) to implement the NDIS must be adequately recognised by the ACT government. Supported Decision Making models are ideal frameworks to prepare our community for the NDIS. However, if the need for supporting skill development, self-advocacy and community awareness is not recognised, the NDIS could as easily be a barrier to the further development of the disability community.¹⁷⁸

Recommendation 23: Government to fund crucial NDIS preparation training as recommended in the Advocacy for Inclusion Budget Submission 2012-13, recognising that the transition to an NDIS will require dedicated consumer oriented preparation,

¹⁷⁶ Thompson, et. al., Op. Cit.

¹⁷⁷ Advocacy for Inclusion, Op. Cit.

¹⁷⁸ Lynch, C., 30 April 2012, Presentation, DANA Conference, Australian Capital Territory

and that the NDIS is an opportune time to begin the transition to Supported Decision Making models.

Recommendation 24: The relative 'newness' of Supported Decision Making models should be viewed positively. The ACT is in a position to pioneer working models of support.

The Road to Full Implementation of Article 12

<p><i>Immediate indicators</i></p>	<ul style="list-style-type: none"> <input type="checkbox"/> Detailed records are kept of all guardianship orders and systematic and transparent reviews of orders are implemented. <input type="checkbox"/> All people subject to guardianship applications and reviews are offered independent representation, information and advocacy support. <input type="checkbox"/> Guardianship Legislation in the ACT is reviewed and adult protection legislation is investigated. <input type="checkbox"/> Informal Supported Decision Making models are acknowledged and encouraged by the Public Advocate and ACAT.
<p><i>Short term indicators</i></p>	<ul style="list-style-type: none"> <input type="checkbox"/> Funded research trials of Supported Decision Making models. <input type="checkbox"/> Across the board training and awareness raising. <input type="checkbox"/> New guardianship orders are made for specific issues and time limited – plenary orders are granted only in rare circumstances.
<p><i>Medium term indicators</i></p>	<ul style="list-style-type: none"> <input type="checkbox"/> Supported Decision Making, including circle and peer networks, safeguard and monitoring systems, provision of resources, and across the board training. <input type="checkbox"/> Disability Inclusion and Awareness Training is mandatory for people working in the disability sector. <input type="checkbox"/> Statutory Supported Decision Making, co-decision making and/or representation agreements are granted instead of guardianship orders. <input type="checkbox"/> Existing guardianship orders are supported to transition into statutory Supported Decision Making, co-decision making and/or representation agreements.
<p><i>Long term indicators</i></p>	<ul style="list-style-type: none"> <input type="checkbox"/> Legislation is amended to meet obligations under CRPD: <ul style="list-style-type: none"> - Guardianship practices are replaced with Supported Decision Making models; - People with disabilities are supported to exercise legal capacity and decision making abilities on an equal basis with other members of the community; - Sound frameworks define and determine legal capacity and restrict the finding of legal incapacity as last resort; - Substitute decision making is applied only in very rare circumstances, if at all, as a last resort, and is time limited and decision specific. - People with disabilities are treated on an equal basis regarding the right to make risky or ‘bad’ decisions; - Medical approach is removed from legislation. <input type="checkbox"/> Existing guardianship orders complete transition into Supported Decision making models.

*Where we
hope to be
by 2100...*

- The community is well practiced and comfortable with Supported Decision Making models, which now occur naturally in the community.
- Guardianship legislation has been abolished.
- Supported Decision Making models have moved away from statutory frameworks to common practice used naturally across the community.
- People with disabilities' decisions are respected and valued by the community. The move towards practices that support and promote the perspective of people with disabilities has facilitated a culture in which people with disabilities are valued, included and can contribute in all aspects of the community.

Conclusion: Implementing Article 12 of the CRPD

It is time for the ACT to assess what disability frameworks might be required to maximise the benefits of the NDIS. With the NDIS will come self-directed funding; a great imperative to develop frameworks that support people with cognitive disabilities to make their own decisions. This new and progressive scheme requires new frameworks – we should not attempt to fit it into old frameworks.

Australia has a way to go in order to meet our obligations as a signatory of the United Nations *Convention for the Rights of Persons with Disabilities*, particularly regarding our guardianship legislations across the nation. Countries such as Canada, where guardianship is almost unheard of, are far beyond Australia in relation to these practices. Commendably, Victoria and South Australia have begun taking steps towards Supported Decision Making practices that better reflect human rights principles. The ACT is beginning to fall behind in these social progressions which aim towards a more inclusive society for people with disabilities.

Article 12 of the CRPD states that it is everyone's right to have equal recognition before the law, and legal capacity before the law. Guardianship, by its nature, does not and cannot support people to access this right because it deliberately denies a person legal capacity with the intention of 'protecting' vulnerable people. Guardianship does not realistically find a balance between protecting vulnerable people and promoting their rights. Substitute decision making silences people with disabilities and discourages them from using or improving their decision making abilities. This serves to heighten their vulnerability. This is particularly the case for plenary orders.

Unfortunately, substitute decision making can be the very instrument used to exploit people with disabilities, particularly when the focus person may not be involved in tribunal processes and reviews, and when the order is difficult or seemingly impossible to remove. Guardians are placed in a position of great responsibility that demands an objective and highly skilled approach in order to determine what decisions a person 'would have made'. An outcome which is arguably unattainable. The likelihood of taking a misguided approach would be compounded by a lack of information and support in the role of guardian.

Guardianship practices do not reflect realistic decision making processes that are used by most people in the community. Decision making capacity exists on a continuum, where at different times, and under different circumstances, all people are better or worse decision makers. Supported Decision Making embraces this inevitable ambiguity in ways that guardianship cannot. Valuing dignity of risk, Supported Decision Making models emphasise the right to make decisions, to learn from bad ones, and to develop the skills to enjoy independence through support and relationships, which nurture these abilities. Most significantly, Supported Decision Making models recognise that all people make decisions with the support of friends, family and experts. The need for support is not considered indicative of lacking decision making capacity. Rather, it reflects what it is for everyone to make important decisions in a social world.

Many people under guardianship orders want to make their own decisions and can be supported to do so. There are cases where people are unnecessarily placed under plenary guardianship because alternatives are not part of common practice. In accordance with the CRPD this must be addressed and Supported Decision Making models are workable alternatives, which are already operating informally in the community. As demonstrated by other states and countries, Supported Decision Making shows great potential for development as a replacement framework.

Supported Decision Making is becoming widely recognised as the way to support people with disabilities to make their own decisions, and exercise their autonomy. Already operating in parts of Canada and legislated for in the UK, Supported Decision Making is currently being trialled in South Australia, and has been recommended by the Victorian Law Reform Commission. The ACT should learn from these examples to develop and trial a model of Supported Decision Making that best suits our community.

Supported Decision Making can operate through a variety of models and relationships, so long as these models support people to build the skills, confidence and networks that will enable them to develop, maintain and exercise their rights and autonomy. The community sector, including community advocacy agencies, are in a prime position to develop models, training, networks and resources to create informal and person-centred Supported Decision Making in the ACT.

There are challenges for the ACT in phasing out guardianship and implementing Supported Decision Making models. Attitudinal barriers and assumptions about the capabilities of people with disabilities will weigh heavily on these significant reforms. It is for this reason that Government and the community will have to work consistently together to not only implement a Supported Decision Making trial, but also to develop community education materials about why Supported Decision Making is so important, and how it would work in the ACT. Supported Decision Making training alongside self-advocacy training will be crucial in assisting our community to make the transition.

With an existing statutory human rights framework, the ACT is well positioned to catch up on the progress of our fellow states, and to pioneer human rights practices through building Supported Decision Making models alongside the roll out of the NDIS. Now is the time to get it right; we must not miss this opportunity.

“Sometimes when consumers don’t have a guardian but have parents that are very involved service providers assume that the parents have the same decision making responsibility as a guardian and will exclude the consumer from decision making or use the parents as the main point of contact.”

Q: WHAT WAS THE TRIBUNAL LIKE? A: “[I] wasn't given any options most of talking was done by PA I made no decisions.”

[we need] **“More information** about stages and types of Guardianship and its permanent nature. Seems like it can't change ever - at least not by request of the appointed guardian.”

“I metaphorically stand in my son's shoes and make decisions I think he would make if he could.”

“I tried to have the financial order removed and my request was refused.”

“My son 26 had ongoing psychiatric issues that had been untreated for seven years, he was diagnosed with acute and aggressive leukaemia in April 2011 and required ongoing chemotherapy and hospitalization. **Doctors and psychiatrist would not talk to me** about what was going in [sic.]”