The Right To Equality

Review of Guardianship Arrangements for Adults with Disabilities in the ACT

Submission to the Law Reform Advisory Committee

Advocacy for Inclusion
July 2015
About Advocacy for Inclusion
Home of the Disability Rights Law Centre

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 is signed onto the ACT Human Rights Act.

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# Implementing CRPD Article 12 in Our Community – Adults with Disabilities Exercising Their Decision Making Rights

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Recommendation 2: The ACT “must closely consult with and actively involve persons with disabilities… through their representative organisations, in the development and implementation of legislation, policies and other decision-making processes that give effect to article 12.”

Recommendation 3: The ACT cannot do nothing and retain the current substitute decision making regime as this is not compatible with human rights principles.

Recommendation 4: The ACT takes a leadership role in implementing the National Decision Making Principles outlined by the Australian Law Reform Commission.

Recommendation 5: The ACT ignores the interpretive declaration placed upon Article 12 at the time the CRPD was ratified.

Recommendation 6: The ACT and all other Australian jurisdictions “recognize persons with disabilities as persons before the law, having legal personality and legal capacity in all aspects of life, on an equal basis with others. This requires the abolition of substitute decision-making regimes and mechanisms that deny legal capacity and which discriminate in purpose or effect against persons with disabilities.”

Recommendation 7: Reforms must go beyond improving written legislation (and its underlying principles) to consider and address the practical and cultural problems that will be encountered in transitioning towards compliance with Article 12 and the expectations of international human rights law.

Recommendation 8: In drafting new legislation, the ACT needs to create statutory language protecting the right to legal capacity on an equal basis for all.

Recommendation 9: New legislation must acknowledge the social model of disability and move away from any recognition of specific disability diagnoses.

Recommendation 10: This review must provide a wide range of measures which respect a person’s autonomy, will and preferences and are in full conformity with Article 12.

Recommendation 11: The “best interests” approach must be abandoned, in favour of the “will and preferences” paradigm, and consigned to the dust bin of history.

Recommendation 12: Traditional understandings of “vulnerability”, “protection”, risk and risk avoidance must be discarded in the development of frameworks that effectively safeguard the rights of people with disabilities to be free from abuse, violence and/or exploitation.

Recommendation 13: To ensure the right to a fair hearing, legal assistance must be offered to any individual who needs (and wants) legal advice and/or representation at tribunal or court hearings.

Recommendation 14: People must be informed of and given support to understand all legal processes concerning their decision-making ability and rights, including their entitlements to:
- request and/or attend Tribunal (and Court) hearings;
- contribute evidence and make their views known (i.e. have a say)
- receive support to participate, whether this is through informal decision support, legal advice or representation, or other advocacy.

Recommendation 15: A specialist service (such as the Disability Rights Law Centre) should be resourced to provide legal advice, representation and support in a manner that enhances the understanding and participation of people with disabilities in legal processes concerning their right to make decisions.
Recommendation 16: Persons applying for guardianship orders, or seeking to be guardians (or representatives) of people with disabilities, should not be relied on to provide information to a person with disability on the nature of the application, the nature of the hearing or to support the person in any hearing.

Recommendation 17: The ACT should establish a scheme to ensure access to free legal representation for any person whose legal capacity is in question.

Recommendation 18: A model should be developed that:
- automatically offers free legal advice and representation for Tribunal hearings to any individuals who cannot afford or otherwise access it;
- retains the right of individuals to make an informed decision to decline to attend the tribunal or court hearing or to access legal representation and/or advice; and,
- reflects the CRPD and builds on the experiences of other jurisdictions.

Recommendation 19: Tribunals or other judicial bodies must not be responsible for deciding whether the person can access free legal representation, support or advice.

Recommendation 20: In those rare circumstances in which it is necessary for a representative to be appointed to make decisions for a person, that person must continue to be given support to convey and assert their will and preferences and be offered opportunities to express objections to or challenge any decisions that have been made on their behalf.

Recommendation 21: Representatives should be expected to account to the tribunal (or court) as to how they have made decisions for a person adhering to guidelines - considering all information available about the person’s past will and preferences, and giving due weight to all indications of what the person would likely want.

Recommendation 22: Coordinated and strategic reforms must be implemented across all relevant areas of ACT law and policy. All reforms must reflect (and be consistent with) the rights and principles of Article 12.

Recommendation 23: Changes to legal and regulatory arrangements must be accompanied by funding investments in community based training and support for people with disabilities, and their family members, friends and carers.

Recommendation 24: Training and awareness-raising must also be directed at people working in government and the private sector, so that all service systems can be brought into compliance with Article 12 and consistency with the changed arrangements.

Recommendation 25: Funding must be invested in training and skills development in key sectors, professions and industries, particularly targeting those with frequent (or otherwise significant) interaction with people needing decision making support.

Recommendation 26: ACT legislation must recognise informal, natural supported decision-making arrangements.

Recommendation 27: A person must retain the right to choose their own decision supporters, and be able to change those supporters at any time.

Recommendation 28: The wishes of the person with disability to have their chosen supporters, informal or formal, involved in decisions should be enshrined in ACT legislation.

Recommendation 29: The ACT should develop a central repository of accessible unbiased information about the various options for supported decision making.
Recommendation 30: Staff at the SDM hub must have considerable expertise in communication and training in order to provide independent explanation, advice and support to people with disabilities.

Recommendation 31: Frontline personnel must receive training in recognising when a person should be referred to (and given support to access) independent information about their decision making rights and the different ways they may choose to receive support to make decisions.

Recommendation 32: Police officers, social workers and other first responders must be trained to recognise persons with disabilities as full persons before the law. This entails training and awareness-raising in these important professions.

Recommendation 33: A person who requires decision making support and who wishes to formalise this through specific legal recognition should have to access a flexible and supportive process through which to achieve this.

Recommendation 34: A person must remain free to direct, and initiate changes to, how they are supported to make decisions.

Recommendation 35: Specific resources should be developed to assist a person needing decision making support to decide what duties and role they would like their chosen supporter to accept and fulfil.

Recommendation 36: Where a person with disability does not have existing appropriate natural relationships for a supported decision making arrangement, they should have access to formal supporters who have undergone appropriate checks and training so that they can select a person they are comfortable with.

Recommendation 37: Representative decision making should be considered a formal model of decision making, which requires independent monitoring and safeguards to maximise transparency and accountability.

Recommendation 38: The following framework should be used to provide guidance on when a representative needs to be appointed:

1. The person’s will and preference cannot be ascertained even after all efforts have been made to communicate with that person and support that person to express their will and preference.
2. All efforts to ascertain a person’s will and preference include at least the following steps:
   a. The person is supported to receive information and communicate their will and preferences pertaining to the relevant decision using all forms of information and communication appropriate to the person. This includes using unconventional communication formats such as computer technology and respect for the person’s cultural and linguistic circumstances.
   b. Communication and decision support is attempted by the person’s significant others, including people with whom the person has existing familiar and trusting relationships and any existing formal or informal decision-supporters appointed by the person.
   c. Where the person does not have such relationships, the person is supported to establish relationships with volunteers with the potential to act as decision-supporters.
   d. Information is provided and communication attempted by other parties who might be involved in the relevant decision.
   e. As much time as possible is allowed for the person to undertake the steps above.

Recommendation 39: The use of advance directives should be encouraged and promoted to the ACT population.

Recommendation 40: Representatives must have access to human rights expertise as needed.

Recommendation 41: Ascertaining the person with disability’s current will and preference must be viewed as an ongoing part of the representative decision making process. All efforts to ascertain the person’s current will and preferences must continue.
Recommendation 42: An appointed representative must keep records to evidence how they have fulfilled and adhered to the Principles and Guidelines in making a decision for a person.

Recommendation 43: The ACT must ensure legal professionals, government officials, ACAT officers and the Public Guardian are fully trained in Article 12 and the principles and practice of supported decision making, and kept informed of all aspects of the legislative, procedural and policy reforms.

Recommendation 44: Legislation, procedures and policy frameworks must be worded using contemporary human rights language and concepts, and structured with clarity and focus, in order to limit the system’s reliance on judicial and administrative discretion. These arrangements must be deliberately crafted to minimise the potential for paternalism or other discriminatory attitudes to influence any determinations made regarding the lives and decisions of people with disabilities.

Recommendation 45: The ACAT to provide formal monitoring and safeguards for people with disabilities in supported and representative decision making arrangements.

Recommendation 46: ACACT monitoring must be a non-negotiable feature of representative decision making, whilst people in supported decision making arrangements may access this resource by choice (with support as needed).

Recommendation 47: People with disabilities in supported decision making arrangements should be entitled to appoint anyone they choose (who is willing and able) to be their decision supporter.

Recommendation 48: People with disabilities should have access to an independent body providing monitoring and safeguards to assist them to manage any potential conflicts of interest as they choose.

Recommendation 49: Paid workers providing essential services (such as support workers, case workers, paid advocates or health professionals) must not be appointed as representatives in order to minimise conflicts of interest.

Recommendation 50: The ACT must invest in sufficiently resourcing supported decision making training and support for people with disabilities and their decision supporters to facilitate cultural change. This includes training and support regarding decision making rights for people with disabilities, supported decision making principles and practices, and changes in legislation.

Recommendation 51: The ACT must resource the community sector to train people with disabilities and their supporters on using supported decision making successfully in the long term.

Recommendation 52: 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.

Recommendation 53: The ACT to fund the development of a program for families and supporters who may be involved in supported decision making. The emphasis should be on valuing skills, talents and interests. This should be co-designed with people with disabilities.
Introduction

Advocacy for Inclusion is a not-for-profit non-government community organisation in the Australian Capital Territory. We provide individual, self and systemic advocacy to people with disabilities to promote their human rights and inclusion in the community. A major part of our direct advocacy work involves working alongside people with disabilities subject to guardianship orders or applications for guardianship orders. Our submission is informed by our experience providing this direct advocacy support to people with disabilities.

For many years Advocacy for Inclusion has been advocating for review of the Guardianship and Management of Property Act, so we are pleased that the ACT Attorney-General has asked the Law Reform Advisory Committee (LRAC) to inquire into the operation of guardianship law, with a focus on human rights and respect for individual autonomy and dignity of persons. The current legislation does not adhere to international human rights law and, specifically, the standards contained in Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Advocacy for Inclusion welcomes this opportunity to contribute to the review process.

Implementing CRPD article 12 in our community – adults with disabilities exercising their decision making rights

A key feature of the current review is the potential it provides the ACT, as a jurisdiction with well-established human rights legislation (the Human Rights Act 2004), to pioneer the transition of Australian law to compliance with the rights, principles and safeguards of CRPD Article 12.

The current review also provides an opportunity to examine the National Decision Making Principles and consider how they reflect the fundamental conceptual shifts of CRPD Article 12 and embody the imperative for effective and forward looking law reform and cultural change.

It is important to use this review process to consider peoples’ experiences with current guardianship arrangements. Various problematic aspects extend across law, procedure and entrenched cultural attitudes and habits.

Advocacy for Inclusion has contributed to many discussions proposing how a reformed adult decision making legislation and practice would operate, including in relation to decision making support, giving effect to will, preferences and rights, the duties of supporters, safeguarding and accountability and the use of representative decision making in very limited circumstances.

It is also important to explore supported decision-making in practice. Strategies and commitment will be required to provide long-term resourcing, information and training to support societal transition towards the implementation of equal rights in decision-making for people with disabilities in accordance with Australia’s obligations.

Recommendation 1: ACT Laws must comply with CRPD Article 12

Leading the way in implementing Article 12

Advocacy for Inclusion notes the human rights focus of the Terms of Reference set by the ACT Attorney-General and commends the efforts of LRAC to include people with disabilities in the consultation, through the provision of the Easy English booklet. The extension of the submission deadline has also provided a greater opportunity for people and organisations to tell LRAC what they think of guardianship. As recommended by the United Nations Committee on the Rights of Persons with Disabilities (the UN Committee) in its General Comment the inclusion and participation of people with disabilities must (continue to) guide all law and policy making processes.

Recommendation 2: The ACT “must closely consult with and actively involve persons with disabilities... through their representative organisations, in the development and implementation of legislation, policies and other decision-making processes that give effect to article 12.”

The ACT should aim to be at the forefront of international expectations in its reforms to adult decision making arrangements. As a human rights jurisdiction the ACT must seize the current review opportunity to lead the way in implementing supported decision-making models and embracing the paradigm shift expected by Article 12. As observed by Caxton Legal Centre in its Submission to the Australian Law Reform Commission Inquiry this is a tremendous task, and the greatest challenges involve

“the political will to endorse change to reflect consistency with a social model of disability [and] to provide sufficient education to the entire community, to stakeholders including all levels of employment and management, and to institutions.”

In undertaking the latter endeavour, the ACT has the advantage of being a geographically small jurisdiction, in which the task of delivering education and training is somewhat less daunting than in other jurisdictions with large populations and service sectors spread over massive areas. Canberra has the potential to become a hub of good practice and innovation in supported decision-making practice.

The ACT should also take a leadership role in the development of a nationally consistent approach to implementing Article 12 and the use of supported decision making. Reforms must be driven and informed by strong commitment to Article 12 and a true understanding of its meaning and the obligations it compels. Specifically, the existence of the interpretive declaration (the effects of which were examined in the ALRC inquiry) should be ignored, as its understanding that the CRPD “allows for fully supported or substituted decision making arrangements” is not a valid interpretation.

That existing guardianship laws are incompatible with Article 12 was reaffirmed and expressly clarified by the United Nations Committee on the Rights of Persons with Disabilities (the UN Committee) in its 2014 General Comment – implementation requires “the abolition of substitute decision-making regimes.” The Committee's Concluding Observations, following Australia’s CRPD review in 2013, recommended Australia review and withdraw its Interpretative Declaration, and replace substitute decision-making with supported decision-making.

The understanding articulated in the Australian Declaration does not comprehend the true meaning and implications of Article 12. Professor Amita Dhanda has described the drafting of the Convention and “the

5 Ibid.
6 Caxton Legal Centre, Submission 67 to the to ALRC Inquiry: Equality, Capacity and Disability in Commonwealth Laws.
8 Committee on the Rights of Persons with Disability, ‘Concluding Observations on the Initial Report of Australia, Adopted by the Committee at Its Tenth Session (2–13 September 2013)’ (United Nations, 4 October 2013) [9], [24].
conservative strangleholds that have attempted to be placed on a forward looking text”. 9 An interpretation that permits substituted or “fully supported” decision-making arrangements, and legitimises frameworks that deprive people with disabilities of legal capacity on a discriminatory basis, ignores or dilutes the universal reach of the capacity formulation in article 12(2). 10 The ACT, as a jurisdiction committed to the fulfilment of human rights, should ignore the interpretive declaration and ensure that current reforms do not perpetuate outdated models of adult decision making. There is some argument that the General Comment has now negated the interpretive declaration. Additionally, the use of s30 of the ACT Human Rights Act provides for the potential to implement the CRPD without the restrictions placed upon it by the ratification process.

The relative newness of supported decision-making must be embraced as an opportunity for the ACT (and Australia) to pioneer the next steps in rights fulfilment for people with disabilities. The challenging nature of the task and potential complexities in practical implementation must not be cited as an excuse for hesitation or delay or for settling on a compromised vision. Doing nothing is not an option. Decisive action in policy, law and practice must be taken to protect and realise the decision making rights of adults with disabilities in the ACT.

Recommendation 3: The ACT cannot do nothing and retain the current substitute decision making regime as this is not compatible with human rights principles.

Recommendation 4: The ACT takes a leadership role in implementing the National Decision Making Principles outlined by the Australian Law Reform Commission.

Recommendation 5: The ACT ignores the interpretive declaration placed upon Article 12 at the time the CRPD was ratified.

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10 Ibid, 461.
The National Decision-Making Principles

1. All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

2. Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

3. The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

4. Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

Advocacy for Inclusion commends the four high level principles recommended by the ALRC. These principles reflect core elements of CRPD Article 12 and provide a strong focus on the human rights principles which must guide ACT guardianship reform. To best translate these principles into a flexible and responsive legal framework, a full appreciation of the underpinning theory is required.

The shift in focus brought by Principle 1 toward decision rights rather than capacity is highly important. This recognition of ‘the right to make decisions’ provides the foundation for the crucial shift, away from the current preoccupation with decision-making capacity assessment, and towards acknowledgement of and respect for decision-making rights. Principle 1 reflects this understanding that people with disabilities will and can make their own decisions and is consistent with the General Comment on CRPD Article 12, which asserts:

The right to equal recognition before the law implies that legal capacity is a universal attribute inherent in all persons by virtue of their humanity and must be upheld for persons with disabilities on an equal basis with others.

Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity (art. 3 (d)) is incompatible with granting legal capacity on an assimilationist basis.

Importantly, this principle refers to all adults having an “equal right to make decisions”. Currently, the law and legislation permits discriminatory treatment towards people with certain disabilities which are considered likely to impair decision making ability – people with disabilities may be required to demonstrate a competency in decision making that other members of the population are not.

Section 8 of the Human Rights Act 2004 (ACT) specifies that “everyone has right to recognition as a person before the law” and “the right to enjoy his or her human rights without distinction or discrimination.”

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11 This section responds to question 3 of the Response Booklet: “What do you think about the National decision-Making principles proposed by the Australian Law Reform Commission? Are they the best way of designing a law that allows people to make decisions in a way consistent with the rights of people with disabilities under the UN Convention?”


Guardianship undermines this right to legal recognition in a discriminatory manner - subjecting the decisions of people with disabilities to a higher degree of scrutiny. In now undertaking law reform in a human rights jurisdiction, any reformulation of legal capacity, in which “a person’s disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity” would be at odds with recognising and respecting the equal right of people with disabilities to make decisions.\footnote{CRPD Committee. (2014). Article 12: Equal recognition before the law. Paragraph 15} As reiterated by the UN Committee’s General Comment:

“Article 12 does not permit such discriminatory denial of legal capacity, but, rather, requires that support be provided in the exercise of legal capacity.”\footnote{Ibid.}

The key difference between substitute and supported decision-making is who is recognised as having decision-making authority. Whereas substitute decision-making allows for a person’s legal capacity to be removed and an alternative decision maker appointed, supported decision-making is where the person with disability is recognised as the decision maker. This must be held as a non-negotiable, fundamental characteristic of supported decision-making. Supporting the person’s will and preference is inherent in this model, since the person with disability is regarded as having the authority over their own decisions. If a person expresses their will and preference through any means, this should be respected. In circumstances when a person’s current will and preferences cannot be determined (for example, if they are unconscious) it will be necessary for a representative to be appointed to make a decision for the person.

It is imperative that the current reform process does not merely amend the terms of the Guardianship and Management of Property Act or narrowly focus on improving its operation. Future ACT laws and policies must reflect these major theoretical and practical shifts in international human rights law. Rather than “fixing” guardianship law to better adhere to, and realise, its (outdated, paternalist) goals and standards, law reform proposals must comprehend and accept that the traditional legal basis for imposing guardianship on people with disabilities has been fundamentally challenged.

Recommendation 6: The ACT and all other Australian jurisdictions “recognize persons with disabilities as persons before the law, having legal personality and legal capacity in all aspects of life, on an equal basis with others. This requires the abolition of substitute decision-making regimes and mechanisms that deny legal capacity and which discriminate in purpose or effect against persons with disabilities.”\footnote{CRPD Committee. (2014). Article 12: Equal recognition before the law. Paragraph 50.}
Consumer experiences of current Guardianship arrangements

The extensive experience of Advocacy for Inclusion in working with consumers and Self-advocates has forged our strong conviction that the current guardianship arrangements do not work. Rather, the legislation, processes and surrounding culture work against the rights, interests and wellbeing of people with disabilities in the ACT. The theoretical underpinning of guardianship law is highly problematic because the legislation operates to enable the discriminatory removal of legal personhood, and entrench harmful paternalism.

In practice, wrongful application of guardianship law further undermines the self-determination of people with disabilities in the ACT as application of the law has commonly failed to adhere to the Guardianship and Management of Property Act's principles of least restriction of individual freedom and of giving effect to the person's wishes as far as possible.

The right to make decisions and exercise control over one’s own life has not been a reality for people with disabilities. In the Advocacy for Inclusion report *Ask me. I make my own decisions*, which studied people’s experience of control and choice, one person who was interviewed felt that much of her life is run by other people – things are done ‘about her without her’. She expressed feelings of powerlessness and indignity:

> Participant: “They make the decisions for me.”
> Interviewer: “How come they do that?”
> Participant: “I don’t know.”
> Interviewer: “How does that make you feel?”
> Participant: “What would you reckon?”
> Interviewer: “Not very good that’s what I would reckon.”
> Participant: “Uh-hmmm.”
> Interviewer: “Is that right?”
> Participant: “I am able to make up my own decisions.”

*(Control and choice study individual interview participant, 2013)*

The guardianship process is often experienced as confusing, demoralising or belittling, and silences the individual’s voice. People with disabilities who are not under guardianship or management orders are also significantly constrained by the cultural expectations that accompany a regime of substitute decision making. In our experience, many service providers assume that if a person has any cognitive disability or even any disability whatsoever, they need a guardian to make decisions for them. Guardianship is seen as a solution to the person’s problems. In some cases service providers push relentlessly for their consumers to be placed under guardianship orders for administrative and risk management purposes. Advocacy for Inclusion also regularly works with people who have no guardianship order yet are responded to by service providers and other agencies (like hospitals) as though there is an order in place.

A ‘solution’ to problems?

Guardianship orders are often viewed as a viable solution to problems faced by people with disabilities in their lives. It is assumed that if someone else is responsible for making decisions on the person’s behalf, their problems will be better dealt with, when usually the problems arise out of a lack of appropriate social supports.

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19 This section responds to question 1 of the Response Booklet: “Tell us about your experiences with the current Guardianship arrangements in the ACT: what has worked for you and/or what problems you have had with them?”
and access to resources, or out of the person with disability not being afforded control over their lives. This practice affects both people with disabilities who have cognitive impairment and those who do not have cognitive impairment, which highlights the serious misconceptions around the purpose of guardianship orders.

**Case study – Gladys**

Gladys is a woman with disability living independently in the community. She has a chronic condition, which was unmanaged, and this was resulting in repeat hospitalisation. She wanted and needed daily drop in home support to help with medications in order to stabilise her health, because she had difficulties maintaining this aspect of personal care independently. Once this support was established, there were a number of teething problems, including that Gladys was frequently not home during her scheduled support.

A case conference was held with Gladys a few weeks later. An allied health professional suggested that Gladys needs a guardian to make these decisions on her behalf, "if Gladys is not home for her appointments she clearly does not understand the consequences to her health", they explained, “what do you have if you don’t have your health? Gladys needs someone to take care of this for her”. Some of the other professionals agreed, and discussions were had about applying for an order.

Gladys wanted to manage her health better but she needed time to settle into her new program. Her advocate suggested that a guardianship order would not help Gladys to manage her condition as it would not resolve her difficulties. What she needed and wanted was social support to help her keep a routine, and although Gladys was missing some of her appointments, she was attending most, and already health professionals reported improvements in her condition.

By the second month into Gladys’ new program she very rarely missed her scheduled drop in support. The health workers had begun to be a bit more flexible, and they realised that although things did not always go perfectly to plan, Gladys’ condition was now well managed. Instead of grilling Gladys every time she occasionally missed an appointment, they set up a system to phone her and remind her just prior to increase the likelihood of Gladys keeping her appointment. Gladys was not hospitalised again, and she really valued the relationship she built with the workers providing drop in support. “They come and see how I’m going, and we have a chat. I like the company,” she said.

**Case study – Ben**

Ben has been working setting tables and taking care of the mail at a nursing home for almost ten years. He is tired of working there and he wants help to look for another job. His brother David, who is his main natural support, told Ben that he’ll never find something else. “You’re lucky to have that job, Ben. You’ve always enjoyed working, just stick through it.” Ben starts missing work altogether, which he’s never done before.

His paid support workers in his group home have started telling him forcefully that he has to go to work and that his tardiness is unacceptable “you’ll lose your job! What will David think of that?” they tell him. One day Ben shouted verbal abuse at his support workers, and he stopped showering and eating properly. “Shut up and leave me alone! I want to try something new. I can’t go back there for another day. I am bored out of my brain!”

David and Julia, the supported accommodation team leader, have a meeting and they think it might be a good idea for David to be Ben’s guardian. Ben’s advocate points out that Ben doesn’t even have a cognitive impairment; his only disability is physical and he uses a wheelchair, so a guardianship order is out of the question.

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23 Based on an actual case at Advocacy for Inclusion. De-identified to protect privacy and confidentiality.
24 Based on an actual case at Advocacy for Inclusion. De-identified to protect privacy and confidentiality.
Everybody experiences difficult life circumstances from time to time. Guardianship simply substitutes responsibility for decision making. It does not provide a solution to complex social and health problems, and can actually make matters worse. Gladys needed help to set up her routine and to put into practice her own decisions, which she had already made in relation to accepting support. Taking responsibility away from her would not have helped her to achieve this. For Ben, if he did have a cognitive impairment and his decision making authority was taken away, this would only have fed the lack of control in his life and compounded his distress at being in a job he no longer found any enjoyment in.

This idea that guardianship can fix people’s problems reflects the paternalistic responses that have historically been used toward people with disabilities, regardless of impairment type. It reflects the cultural belief that people with disabilities do not know their own best interests, and that they should be protected by taking away decision-making authority.

Administrative convenience

A number of Advocacy for Inclusion’s consumers have been subject to guardianship orders prompted by service providers. This has usually been initiated to accommodate the organisation’s preference to swiftly and easily reach decisions in regards to the person’s support arrangements. Rather than getting permission directly from the person concerned they can bypass them and ask the guardian to approve the desired changes. Where the appointed guardian is amenable to granting permission or accepting proposed changes, a guardianship order will maximise the ease for the service provider to make unfavourable or unwanted changes to a person’s support, as the opinions (and any doubts, misgiving or objections) of the person most directly impacted by the changes can be circumvented as a barrier.

Even those service providers motivated to deliver high quality supports to consumers seek any available shortcut when the person with disability requires more extensive explanation and support to understand, evaluate, select or approve the different service options. This bureaucratic culture is highly reliant on, and conducive to the continued use of substitute decision making and tends to protect the status quo and impede service improvements. By excluding the person with disability from any decision making about their own supports, service providers avoid spending time and effort in order to gain administrative convenience, but they also lose the value and advantages that can be derived from the perspectives and insights of informed consumers engaged in the process of choosing their own supports.

Case study – Fran

Fran is about to begin a National Disability Insurance Scheme (NDIS) planning process. She is an articulate woman, but she needs time to organise her thoughts. Sometimes she needs to go over things a few times, and she really appreciates having her advocate with her during meetings to relay the discussions and remind her of what happened.

Her current supported accommodation provider presented her with a contract, outlining what services they will offer her with the new NDIS system. Fran had no idea what to think or say. She didn’t sign the contract, because she knows not to sign things that she doesn’t understand. This prompted the CEO of the service provider to apply for a guardianship order. Fran and her advocate did not find out until she was sent a notice from ACAT.

The advocate looked at the contract with Fran, which was full of legal jargon, was in small print, and was not laid out in an easy to follow format. Fran’s advocate found it very difficult to comprehend too, and told Fran that she made a good decision not to sign the contract on the spot. With the NDIS Fran has the opportunity to go

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25 Based on an actual case at Advocacy for Inclusion. De-identified to protect privacy and confidentiality.
26 The ACT Civil and Administrative Tribunal.
through a planning process independent of her current provider, and she might yet decide that she wants a
different support plan or perhaps even a different provider altogether.

When Fran and her advocate sat together a few times to talk through her goals, she had a very good idea of
what she wanted her supports to look like. She could certainly make her own decisions about her supports.
Regardless, the guardianship application went ahead and Fran’s nephew Tim was appointed her guardian.
This caused tensions as Fran had decided that she wanted to try a new provider. She was unhappy with how
she was treated by the current service. She viewed the NDIS as her opportunity to get the support that she
wanted and felt comfortable with instead of simply taking what was given to her. However, Tim was concerned
that this was a risky decision, since Fran had been with that provider for many years, and it seemed like a
sensible and secure option to him to continue with them.

Ultimately the guardianship order was made to achieve security and administrative convenience for the service
provider. The provider still had a lot of influence over what was delivered to Fran, and when Fran requested
changes to her current supports they cited organisational barriers to fulfilling her wishes.

Fran knew what she wanted, but because it was inconvenient for her service provider a guardian was
appointed. The guardian made a decision without consulting Fran because this was an easier option than
seeking a new service provider. Even though Fran could make this decision she was sidelined for the
convenience of others.

Incongruence between legislation and practice

There is a problematic culture surrounding the lives of people with disabilities. This includes a significant
preoccupation with risk management and the pervasive attitude that people with disabilities do not know their
own interests, and therefore need protection from themselves and from society. Current guardianship practices
are a product of this culture and major cultural change will be needed to address this. 27

Current ACT guardianship legislation incorporates some principles to promote a person’s autonomy. These
include an expectation that the guardian will seek to establish the person’s will and preferences to inform their
decisions. 28 However, direct individual advocacy experience shows that a person’s will and preference is often
not regarded as a priority component of a guardianship arrangement. The guardian is seen as the person with
decision-making authority. Ascertaining the person’s will and preference is treated as an optional addition to
the decision-making process rather than a fundamental decision-making principle. Advocacy for Inclusion
regularly queries whether guardians are even aware of their legislative obligation to ascertain a person’s will
and preferences.

Where a person’s wishes are ascertained, they bear little weight. Our consumers, and people with disabilities
involved in our research, tell us that they are not given a chance to voice their wishes, or when they are, they
are not viewed as having capacity or authority:

“[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.” 29 30

27 Measures to drive cultural change are explored further below.

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In 2012, Advocacy for Inclusion surveyed guardians and found that there is limited education and support offered to guardians or managers about the responsibilities of their role and how to practically fulfil the obligations of the decision making principles in Sections 4 and 5A of the Guardianship and Management of Property Act. One guardian also believed there should be more:

"information about stages and types of Guardianship and its permanent nature - seems like it can't change ever..."

Appeals against guardianship orders can be made to the Supreme Court, though a review process usually takes place through the ACAT. In our experience, once they are in place orders are unlikely to be rescinded by any means such as review by the Tribunal, request by guardian or the protected person, or with changed decision making skills. Survey respondents stated:

"Getting the Guardianship Order was 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 an Order, it defaults to the Public Trustee."

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

In the ACT the Tribunal has now ceased granting plenary orders. Yet, in practice, guardians and involved parties assume that the guardian has the right and responsibility to make decisions concerning any area of the protected person's life. Many service providers, professionals and support workers fail to check a person's guardianship order to verify who is legally responsible for making a particular decision or what domains of decision-making an order covers. For consumers at Advocacy for Inclusion who have a guardianship order covering one or more specified areas, it is often assumed by other people they interact with, such as community workers and health professionals, that the guardian is the default go-to person regarding all areas of decision making. This assumption further diminishes the small amount of control a person may be able to assert over various other aspects of their life.

Recommendation 7: Reforms must go beyond improving written legislation (and its underlying principles) to consider and address the practical and cultural problems that will be encountered in transitioning towards compliance with Article 12 and the expectations of international human rights law.


32 Ibid.

33 ACT Supreme Court, Supreme Court Jurisdiction http://www.courts.act.gov.au/supreme/about_the_court/court_jurisdiction_and_history


37 However, the Application Form on the ACAT website has retained this language, as applicants must certify that they are prepared to act as plenary or limited guardian or manager if appointed. Furthermore, the limited guardianship orders commonly cover an extensive list of matters, including day to day areas of decision making.
Testing decision making capacity

The tests and assessments used to determine decision-making capacity are subjective and anchored in socially constructed norms around what it means and looks like to have decision-making capacity. They are based in the assumption that the inner workings of a person’s mind can be accurately and objectively assessed, when this is simply not the case. In their General Comment on Article 12, the UN Committee observed:

_The concept of mental capacity is highly controversial in and of itself. Mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity._

This dangerous vagueness and subjectivity is present in the ACT legislation, which does not provide clear guidelines on how “impaired decision making capacity” may be demonstrated or determined. ACAT publishes some data in its Annual Reports relating to the number and broad categories of guardianship matters heard in the ACT. Yet, it remains unclear from the information available in official reports, websites and case law, exactly how a person’s capacity is evaluated or tested.

Section 5 of the _Guardianship and Management of Property Act_ requires the protected person’s decision making ability to be impaired “because of a physical, mental, psychological or intellectual condition or state”. Referring to a “condition” or disability as an aspect of capacity is a common but problematic approach in guardianship legislation. The reference refuges questions of capacity from being decision specific, and instead relies on interpretations and assumptions of disability. This ignores the expectation under the CRPD, and the _ACT Human Rights Act_, 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” and “illness” in the legislation indicates and further entrenches the discriminatory connection between particular disabilities or diagnoses and the questions of legal capacity. Although a person’s disability or a diagnosis is not by itself a basis for a finding of impaired decision-making ability under the legislation, the wording reflects the historically used medical / diagnostic approach – statutory regimes in which a diagnosis of certain conditions or medical certification of loss of cognitive capacity was often sufficient to automatically trigger imposition of guardianship. The “medical model” has now been superseded by the social model of disability as used by the CRPD, and the outdated language of the current legislation must be discarded. The need for new legislative language is also highlighted in the UN Committee’s General Comment.

**Recommendation 8:** In drafting new legislation, the ACT needs to create statutory language protecting the right to legal capacity on an equal basis for all.

**Recommendation 9:** New legislation must acknowledge the social model of disability and move away from any recognition of specific disability diagnoses.

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41 Section 8. _Human Rights Act 2004_ (ACT).
42 Attorney General’s Department of New South Wales. (2006). _A Discussion Paper: Are the Rights of People whose Capacity is in Question being Adequately protected?_
Although Section 6A limits the characteristics or behaviours to be considered relevant to findings of impaired decision making ability, the Guardianship and Management of Property Act allows a broad ambit of causal factors to be considered in determining whether a person has impaired decision making ability in relation to any matter. The Guardianship and Management of Property Act does not clearly define “decision making ability” or “impairment”, but rather attention is focused on making assessments of “likelihood of need” or “unreasonable risk”, and whether a “person’s needs” will be met, or whether a “person’s interests” will be significantly adversely affected. This indirect and imprecise approach allows for a high degree of subjective interpretation (and therefore paternalism and risk aversion) in the appointment of guardians.

The current 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 risk and assists them to meet their needs. The legislation unnecessarily hinders decision making skill building and creates a social and political environment that encourages people with disabilities to be dependent.

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. It could be argued that for many there is a presumption of incapacity and that the person is required to prove otherwise. This contradicts all natural justice and human rights frameworks.

When a person is assessed as not having decision-making capacity, they are effectively being judged upon whether they assimilate to decision-making capacity norms. They can be denied their legal capacity based on this judgement. The CRPD General Comment on Article 12 notes:

The right to equal recognition before the law implies that legal capacity is a universal attribute inherent in all persons by virtue of their humanity and must be upheld for persons with disabilities on an equal basis with others.

Any models that permit the denial of a person’s legal capacity on the basis of their assessed decision-making ability are not compliant with CRPD Article 12 (and arguably, therefore, also fail to be compliant with the ACT Human Rights Act). This was made clear in the Concluding Observations by the United Nations Committee on the Rights of Persons with Disabilities (the UN Committee), when it recommended that Australia:

“take immediate steps to replace substitute decision-making with supported decision-making and… provide a wide range of measures which respect a person’s autonomy, will and preferences and are in full conformity with article 12.”

Recommendation 10: This review must provide a wide range of measures which respect a person’s autonomy, will and preferences and are in full conformity with Article 12.

Subjectivity of “best interests”

The “best interests” principle, and its usefulness as a legal concept, has been the subject of much debate in a range of fields. It has been criticised as an indeterminate standard, vulnerable to biased or unpredictable

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Conclusion, 12-14.


47 Concluding observations on Australia, adopted by the Committee at its tenth session 4/10/2013. CRPD/C/AUS/CO/1. pp49-50.


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The process of interpreting the principle is inherently value-laden. The discretionary nature of the “best interests” standard leaves it vulnerable to exploitation by decision makers. As Justice Brennan stated in Marion’s Case:

“The best interests approach depends upon the value system of the decision-maker. Absent any rule or guideline, that approach simply creates an unexaminable discretion in the repository of the power.”

In the context of substitute decision making, Dunn, Clare, Holland and Gunn identified procedurally and conceptually inconsistent decisions in case law that applies the changing “best interests” standard:

“These anomalies are of two types: the application of “best interests” to overrule capacitous decision-making on paternalistic grounds and incoherence about the determination of an individual’s “best interests”, where the interests of others are integrally tied up in the outcome of the decision.”

In relation to 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. The “best interests” principle is a malleable and persuasive phrase that can be used to hide or obscure other interests influencing or taking precedence over the rights and interests of the person. For instance, a seemingly well intentioned argument that imposing a guardianship order, as the most bureaucratically convenient arrangement, would be in the “best interests” of the person with disability masks the way in which the preferences of a service provider or carer pull focus away and detract from a comprehensive, clear-sighted consideration of the preferences, rights and interests of the person with disability.

The “best interests” principle is not a safeguard which complies with Article 12 in relation to adults.

Recommendation 11: The “best interests” approach must be abandoned, in favour of the “will and preferences” paradigm, and consigned to the dustbin of history.

The concept of vulnerability

The paternalistic idea that people with disabilities are unable and/or are not entitled to participate in decisions concerning the broader community, and indeed decisions regarding their own lives, renders people with disabilities vulnerable and marginalised. People with disabilities experience high rates of violence, yet because they are often not viewed as credible they are less likely to have their concerns acknowledged and taken seriously. As the social model of disability becomes more broadly understood, it is increasingly recognised that people with disabilities are not inherently more vulnerable through personal attributes such as cognitive or physical impairment. Hilary Brown suggests that a person is only


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“vulnerable to the extent that their rights are not upheld or insofar as they are excluded from, or unable to gain access to, mainstream mechanisms for protection and redress.”^67

People with disabilities are made vulnerable through the social and cultural environment, which places them in positions of powerlessness. They are devalued and disadvantaged by an inaccessible society, resulting in high rates of poverty, victimisation and social isolation, under-employment and low levels of education.\(^{58} 59 60 61 62 63\)

Guardianship compounds vulnerability, it does not negate it. Guardianship orders necessitate an imbalance of power, unequal access to legal assistance and uneven valuing of knowledge in both procedure and outcome.\(^{65}\)

The perception that guardianship protects and cares for people with disabilities is unrealistic and must be challenged,\(^{66}\) as there are numerous and harrowing examples where this is not the case.

Beyond the practice of formal substitute decision making through the provision of orders, a ‘culture of guardianship’ exists, brought about by long held protectionist beliefs about people with disabilities and their incapacity coupled with a focus on risk management. Advocacy for Inclusion has worked on numerous cases where the idea of ‘reasonable risk’\(^{67}\) (and “dignity of risk”)\(^{68}\) is conservatively viewed among support agencies, families and carers of people with disabilities. This means that people with disabilities, and particularly those under guardianship orders, are prevented from taking risks that people without disabilities may freely take. Conventional risk management approaches are typically technical and generally treat the person as:

> “an object to be assessed by the ‘experts’ rather than as an agent in their own lives, part of a family, community and society, with legal rights and choices.”\(^{69}\)

In contrast, ‘risk enablement’ or “dignity of risk” is based on

> “the idea that the process of measuring risk involves balancing the positive benefits from taking risks against the negative effects of attempting to avoid risk altogether.”\(^{70}\)

Arguably, legal assessments of decision making capacity generally operate not to meaningfully reduce the levels of risk faced by people with disabilities but rather to serve the risk management needs of service

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\(^{60}\) OECD. (2009). Sickness, disability and work: Keeping on track in the economic downturn – Background paper.


\(^{65}\) The right of people with disabilities to take reasonable risks is reflected in the General Principles guiding the *National Disability Insurance Scheme Act 2013*, in Clause 4 of Section 4 which states “People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports”.

\(^{66}\) 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.


providers and institutions who will engage with the person under the guardianship order.\textsuperscript{71} Advocacy for Inclusion has explored this area in more detail in:

- ‘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’\textsuperscript{72}
- ‘“Ask me. I make my own decisions”: Report on the findings of a study into the experience of control and choice of people with disabilities in the ACT’.\textsuperscript{73}

Alternative approaches to safeguarding the rights of people to be free from abuse and violence do exist and must be explored in the ACT.\textsuperscript{74} For instance, UK legislation 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.

**Recommendation 12: Traditional understandings of “vulnerability”, “protection”, risk and risk avoidance must be discarded in the development of frameworks that effectively safeguard the rights of people with disabilities to be free from abuse, violence and/or exploitation.**

**Lack of legal representation and access to justice**

“Accessibility of the law depends on awareness of legal rights and of available procedures to enforce such rights”\textsuperscript{75}

Advocacy for Inclusion has experienced numerous cases in the ACT where guardianship orders are placed on people who have not been adequately involved or informed throughout the process; and therefore, have been given little opportunity to confirm their capacity or express their wishes in relation to the order. In our experience, the person whose capacity is in question rarely receives independent legal or informational support, through the initial stages of a guardianship order request or at the tribunal hearing or reviews. Advocacy for Inclusion has often found the person whose legal capacity is in question does not attend the guardianship hearing and it may even have occurred without their knowledge. Similarly the person is often unaware of when their order is coming up for review.

Guardianship orders are made through tribunal proceedings, which are less formal than court proceedings. This can lead to a lack of legal representation for people subject to an application for guardianship orders because it is not expected that participants will not need the special knowledge or skills provided by a legal representative (which is often important in a court environment) to represent and defend their interests – tribunal processes are less adversarial and more inquisitorial. There is understandable resistance to ‘creeping legalism’ in tribunal processes, as many are concerned that increasing formality may undermine the intended flexibility and accessibility of bodies like ACAT.\textsuperscript{76} However, the recent Productivity Commission inquiry into access to civil justice recognised that:

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\textsuperscript{71} Victorian Law Reform Commission, 2012, Guardianship: Final Report 24, Melbourne
\textsuperscript{73} Advocacy for Inclusion. (2013). “Ask me. I make my own decisions”: Report on the findings of a study into the experience of control and choice of people with disabilities in the ACT. http://www.advocacyforinclusion.org/index.php/publications-home/decision-making 29-31
\textsuperscript{74} Directions for reforms are discussed below in the section on Safeguards and Accountability.
\end{flushright}
Legal representation is rarely restricted in mental health and guardianship areas, yet “given the nature of these matters, most representation is provided by the legal assistance sector and depends on the resources allocated to those jurisdictions.”

Given the significance, and human rights implications, of removing a person’s decision making rights, the absence of meaningful access to legal representation severely undermines the fairness, legitimacy and accountability of guardianship processes. Further, the assumption that legal assistance will not be required in a Tribunal setting denies people with disabilities automatic access to legal representation as would happen in criminal justice proceedings. This places the onus on the person to assert their right to question the guardianship application or review, rather than protecting their right to be assumed to have capacity as per CRPD Article 12.

This lack of natural justice has been a major issue experienced by consumers at Advocacy for Inclusion. Once orders are made, the person with disability is placed in a position of extreme powerlessness. Advocacy for Inclusion is concerned about the rights of people with disabilities who are subject to ACAT proceedings and have not been offered legal representation, nor have any meaningful access to independent legal information or advice. In some cases, our individual advocates have organised to have this put in place for a consumer or we have been able to source pro bono legal representation to ensure that the person is able to be fairly and effectively engaged in the process. Unfortunately such supports are difficult to source, and are only available for the most difficult cases.

In its General Comment 32 on Article 14 of the International Covenant on Civil and Political Rights (ICCPR), the United National Human Rights Committee observes that:

“The availability or absence of legal assistance often determines whether or not a person can access the relevant proceedings or participate in them in a meaningful way… States are encouraged to provide free legal aid in [civil/non-criminal] cases, for individuals who do not have sufficient means to pay for it. In some cases, they may even be obliged to do so.”

Guardianship matters do not currently attract the same “guarantee of legal assistance” as criminal proceedings, yet the rights and freedoms at stake for the individual are fundamental. Indeed, the potential restrictions on autonomy that a Tribunal may authorise in guardianship matters are analogous to those faced by a defendant in criminal proceedings. Therefore, we contend that whenever a person’s legal capacity is called into question before a tribunal (or court) there is a positive obligation on governments to not only allow the person to seek and access legal representation, but also to provide legal assistance to individuals who cannot afford it (or whose right to make financial decisions has been removed or limited in some way, whether in law or in practice).

**Recommendation 13: To ensure the right to a fair hearing, legal assistance must be offered to any individual who needs (and wants) legal advice and/or representation at tribunal or court hearings.**

The current culture surrounding guardianship practices is such that people with disabilities are not always informed of a guardianship application being sought on their behalf, nor are they involved throughout the
tribunal proceedings, including in reviews of orders. Some Advocacy for Inclusion consumers have only learned that they are subject to orders or that an order has been reviewed when they receive a copy of the final order in the post. ACAT’s 2013-14 Annual Report states:

“Review hearings are usually conducted “on the papers”, based on information gathered from the protected person, the guardian or manager and any carer or other interested party. Full hearings are scheduled at the request of the protected person, or if the information provided (or not provided, as the case may be) indicates that there has been a change in circumstances.”

However, the ability of the ‘protected person’ to request a full hearing, participate in that process or contribute relevant evidence will depend on their access to information, support and advocacy. Mere notification through a technically worded letter will be inadequate if:

- the person does not directly receive their mail (approximately half of Advocacy for Inclusion consumers do not receive their mail);
- their guardian restricts their access to mail, or does not fully reveal or explain the correspondence; or,
- where no support is provided to the person to help them understand its meaning.

There is an inherent conflict of interest in relying on the person applying for the guardianship order, or who seeks to be the guardian, to also provide information to the person with disability on the nature of the application. Similarly, applicants or existing guardians cannot provide an independent perspective to the person with disability nor support the person to express their views or defend their interests during this process.

If a person under a guardianship order is not supported to understand the nature of the process and its legal implications, or properly notified of an upcoming review of an order, they have no real opportunity to put forward relevant evidence about changes in their lives or in their decision making skills; nor is there a chance for the person to receive independent legal advice, seek to be legally represented, or indeed to meaningfully engage in a legal process in which their fundamental legal rights are at stake. This situation is not consistent with:

- the right to fair hearing, which is considered fundamental to most legal traditions and systems and is reiterated in Section 21 of the Human Rights Act (ACT);
- “The right to equality before courts and tribunals and to a fair hearing” in Article 14 of the ICCPR;
- the natural justice principles of civil and administrative law;
- “providing access by people with disabilities to the support they may require in exercising their legal capacity”, as expected in CRPD Article 12(3);
- the “access to justice” described by CRPD Article 13, which includes an expectation of procedural accommodations for people with disabilities “in order to facilitate their effective role as direct and indirect participants… in all legal proceedings, including at investigative and other preliminary stages.”

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81 Ibid.
82 In this way, guardianship hearings are highly analogous to Tribunal hearings for mental health orders and reviews.
83 Everyone has the right to have … rights and obligations recognised by law, decided by a competent, independent and impartial court or tribunal after a fair… hearing, s21 of the Act
84 International Covenant on Civil and Political Rights article 14
Recommendation 14: People must be informed of and given support to understand all legal processes concerning their decision-making ability and rights, including their entitlements to:

- request and/or attend Tribunal (and Court) hearings;
- contribute evidence and make their views known (i.e. have a say);
- receive support to participate, whether this is through informal decision support, legal advice or representation, or other advocacy.

Recommendation 15: A specialist service (such as the Disability Rights Law Centre) should be resourced to provide legal advice, representation and support in a manner that enhances the understanding and participation of people with disabilities in legal processes concerning their right to make decisions.

Recommendation 16: Persons applying for guardianship orders, or seeking to be guardians (or representatives) of people with disabilities, should not be relied on to provide information to a person with disability on the nature of the application, the nature of the hearing or to support the person in any hearing.

The experience of being unrepresented and unheard may actually damage a person’s psychological wellbeing and their confidence in exercising their decision making and self-advocacy skills. Despite the informal and non-adversarial setting, people unrepresented at mental health tribunals have felt understandably intimidated, stressed and confused during the process.85 A proceeding perceived as unfair, and disregarding of the person’s perspectives, may be psychologically damaging to the individual.86

In contrast, where people are represented before mental health tribunals or courts, they feel a sense of empowerment, and of being listened to and having “a voice”.87 Opportunities to participate and the degree to which people feel treated with dignity and respect naturally influence the person’s perceptions and experiences of the process as “fair”.88 The opportunity afforded by legal representation to fully and clearly articulate one’s position, is of important dignitary and participatory value.89

The potential for schemes that ensure access to legal representation at tribunal hearings should be considered in developing policy and drafting legislation in this area. Models that provide (free) legal representation before mental health tribunals for all individuals who are (or may be made) subject to an order should be explored and emulated. Examples in Australia include the Northern Territory,90 and Tasmania.91 Models should be assessed

91 Section 131 Mental Health and Related Services Act (NT) imposes an obligation on the Tribunal to appoint a legal practitioner (and order the Territory to pay part or all costs) if it “considers the person should be represented at the hearing”. In recent years (2012-2014), 100% of patients were legally represented before the Northern Territory Tribunal.
92 Free representation is guaranteed by a scheme developed by Advocacy Tasmania Incorporated, in which trained law students, not admitted practitioners, are provided as legal advocates for patients. In recent years, roughly half of those appearing before the Tribunal are represented by the scheme. See further, Debra Rigby, ‘Tasmania Mental Health Representation Project – A Practical Example of Therapeutic Jurisprudence’ (Paper presented at the 3rd International Conference on Therapeutic Jurisprudence, Perth, Western Australia 7-9 June 2006), Valerie Williams, ‘The Challenge for Australian Jurisdictions to Guarantee Free Qualified Representation Advocacy for Inclusion – Submission to the Review of Guardianship Arrangements for Adults with Disabilities in the ACT
and designed against a CRPD framework. Leaving to the Tribunal's discretion whether legal representation will be provided to the person at no cost would allow a conflict of interest and should be avoided. People who are subject to proceedings must retain the right to make an informed decision to decline legal representation if they so choose. Similarly, with greater measures to ensure people are aware of and can access transport and other support to attend and participate in scheduled tribunal hearings, the person must still have a right to refuse to attend.

Recommendation 17: The ACT should establish a scheme to ensure access to free legal representation for any person whose legal capacity is in question.

Recommendation 18: A model should be developed that:
- automatically offers free legal advice and representation for Tribunal hearings to any individuals who cannot afford or otherwise access it;
- retains the right of individuals to make an informed decision to decline to attend the tribunal or court hearing or to access legal representation and/or advice; and,
- reflects the CRPD and builds on the experiences of other jurisdictions.

Recommendation 19: Tribunals or other judicial bodies must not be responsible for deciding whether the person can access free legal representation, support or advice.

Accountability of substitute decisions

Accountability is a major issue with guardianship. The feedback we have received through our direct practice and research has indicated 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’.  

A person under a guardianship order is placed in a weak position in terms of accessing independent legal information, support or representation or of challenging the appointment of a particular guardian or any decisions made on their behalf. People under guardianship orders tend to be poorly informed of the legal processes imposing guardianship and some may never receive a full independent explanation of the legal principles, their entitlements or the responsibilities of their guardian in making substitute decisions. Many are unaware of the (existing) decision making principles that appointed guardians are required to follow under the current Guardianship and Management of Property Act, the extent to which their wishes should be given effect and considered in decisions, or of their ability to request the Tribunal schedule a full hearing when the guardianship order is reviewed.

Making substitute decisions guided by principles of advancing and protecting the person’s interests is a highly subjective exercise. A UK study conducted amongst support workers in residential homecare found that decisions were typically made according to the personal goals and values of the supporter rather than those of the supported person. Similarly, the responses to the Advocacy for Inclusion survey conducted in 2012 for ‘Supported Decision Making, Legal Capacity and Guardianship’ demonstrated that people feel decisions are being made for them without consideration of their expressed wishes.

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92 As discussed above, the person under a guardianship order is placed in a weak position in terms of accessing independent legal information, support or representation, challenging the appointment of a guardian.


Recommendation 20: In those rare circumstances in which it is necessary for a representative to be appointed to make decisions for a person, that person must continue to be given support to convey and assert their will and preferences and be offered opportunities to express objections to or challenge any decisions that have been made on their behalf.

Recommendation 21: Representatives should be expected to account to the tribunal (or court) as to how they have made decisions for a person adhering to guidelines - considering all information available about the person’s past will and preferences, and giving due weight to all indications of what the person would likely want.

Case study – Peru forges ahead

Peru’s word-first proposal to implement the CRPD, specifically Article 12, is ambitious and an exciting step towards equality for persons with disabilities. Formally and informally and through guardianship arrangement, persons with disabilities have previously been denied fundamental rights. The campaign to abolish guardianship focused highlighting the issues with guardianship and enlightening the country and politicians about the need for reform.

In 2015 a Special Commission of Congress reviewed Peru’s Civil Code and submitted the proposal to the Commission of Justice and Human Rights in March. The Commission’s membership included congresspersons, members of the judiciary, the disability Council (which represents the executive branch), academics and members of society. The proposal recommends amending 80 articles in the Civil Code in order to provide full recognition of legal capacity to persons with disabilities and other groups of people historically deprived of legal capacity, thus eliminating all forms of substitute decision-making, consistent with Article 12. The importance of reasonable and accessible support arrangements is emphasised.
The way forward – the ACT takes the lead

Advocacy for Inclusion envisages adults with disabilities in our community exercising their decision making rights, with the support they need to do so. This vision requires law reform driven by and committed to the rights of people with disabilities to self-determination, equal recognition before the law and equal enjoyment of legal capacity.

Successful implementation of Article 12 will also require coordinated reforms to other areas of law. Consistent and supportive measures to drive cultural attitudinal change across all policy areas and sectors will be integral to this success. Considerable investment will be needed (particularly in community sector resourcing and assistance to community-based organisations, networks and groups) to ensure the provision of appropriate support and training is available to people with disabilities, family members, carers and support workers and to personnel across relevant statutory agencies, professions services sectors and industries: for instance disability services, the justice system, health care, financial institutions etc.

**Recommendation 22:** Coordinated and strategic reforms must be implemented across all relevant areas of ACT law and policy. All reforms must reflect (and be consistent with) the rights and principles of Article 12.

**Recommendation 23:** Changes to legal and regulatory arrangements must be accompanied by funding investments in community based training and support for people with disabilities, and their family members, friends and carers.

**Recommendation 24:** Training and awareness-raising must also be directed at people working in government and the private sector, so that all service systems can be brought into compliance with Article 12 and consistency with the changed arrangements.

**Recommendation 25:** Funding must be invested in training and skills development in key sectors, professions and industries, particularly targeting those with frequent (or otherwise significant) interaction with people needing decision making support.

**Guidelines for Decision-Making Support**

- **a. persons who require decision-making support should be supported to participate in and contribute to all aspects of life.**
- **b. persons who require decision-making support should be supported in making decisions.**
- **c. the role of persons who provide decision-making support should be acknowledged and respected, including family members, carers and other people chosen to provide support.**
- **d. persons who require decision-making support may choose not to be supported.**

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95 This section responds to question 4 of the Response Booklet: "What do you think about the Australian Law Reform Commission’s Guidelines for decision-Making Support. Do you think they are useful? Is there anything else that should be there?"
These guidelines reflect key understandings of supported decision making. As discussed above, the paradigm shift of Article 12:

“compels law reform to assume that everybody enjoys legal capacity and redirects our focus away from deficiencies (which are in fact universal and not confined to persons with disabilities) towards supports that enable individuals to make decisions for themselves and expand their capacities to do so. The notion of ‘supported decision-making’ simply builds on this universal reality and extends it to persons with disabilities.”  

Supported decision-making is about supporting the person with disability to make their own decisions. The person appoints their own decision supporter/s. A decision supporter can never be appointed to a person by someone else on their behalf.

If a person expresses their will and preference through any means, this should be respected. The person makes decisions about their own life, relative to their own capacities, values, beliefs, preferences, knowledge, experiences and circumstances, which is how everyone makes all decisions. However, in order for the person to exercise their decision-making capacity and legal capacity to the fullest extent, the person might choose to access decision-making support.

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. Supported decision-making 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”, which are expressed through the decisions they make.

Decision making is a contextual process and the existence of accessible information in appropriate formats and social supports can enhance a person’s capacity to make decisions. Further, a person can have the capacity to make some decisions and be supported to make others. This should inform the way adult decision making arrangements are redesigned and put into operation in the ACT.

Supported decision making acknowledges the role of social support in decision making by all people and also acknowledges 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. The decisions of people with disabilities must not be subjected to more scrutiny than those made by the general population. As we recommended to the ALRC, one priority for Australian reforms is to ensure that informal supported decision-making arrangements are acknowledged and supported by Commonwealth, State and Territory laws.

**Recommendation 26: ACT legislation must recognise informal, natural supported decision-making arrangements.**

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


Recommendation 27: A person must retain the right to choose their own decision supporters, and be able to change those supporters at any time.

Recommendation 28: The wishes of the person with disability to have their chosen supporters, informal or formal, involved in decisions should be enshrined in ACT legislation.

Supported decision-making recognises that when a person makes a 'bad' decision, this does not mean that the person cannot make decisions altogether.\(^{103}\) 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.\(^{104}\) 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.\(^{105}\)

**Guidelines for assessing support needs**

In assessing what support is required in decision-making, the following must be considered:

a. All adults must be presumed to have ability to make decisions that affect their lives.

b. A person must not be assumed to lack decision-making ability on the basis of having a disability.

c. A person’s decision-making ability must be considered in the context of available supports.

d. A person’s decision-making ability is to be assessed, not the outcome of the decision they want to make.

e. A person’s decision-making ability will depend on the kind of decisions to be made.

f. A person’s decision-making ability may evolve or fluctuate over time.

Many of the understandings discussed above are well reflected in the *Guidelines for assessing support needs*. Crucially, the *General guidelines for decision making support* state, “persons who require decision making support may choose not to be supported”. Therefore supported decision making arrangements are not something that can be imposed upon a person or the people supporting them. It is imperative that people with disabilities remain in control of whether (and in what manner) they wish to engage with support in making decisions.

Policy and law reform must endeavour to establish a framework that is responsive to the needs of adults with disabilities to access information and support about decision making options. This should include measures to ensure people have ready access to a clear unbiased explanation of how supported decision making works, and to relevant information and resources. Rather than a system that imposes any “assessment” of an individual’s support needs, focus should be on optimising the systemic capacity to respond to a person in need of decision support, through information and support to access and understand resources on decision making.

\(^{103}\) As discussed above, the assessment of whether a decision is in a person’s “best interests”, and what should be categorised as a “good decision” or a “bad decision” is a highly subjective and culturally informed process that tends to reflect and reinforce the pre-existing values of the judicial authority or substitute decision maker.

\(^{104}\) Attorney General’s Department of New South Wales. (2006). *A Discussion Paper: Are the Rights of People whose Capacity is in Question being Adequately protected?*


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The ACT should establish a central collection/repository (hub) for supported decision making information and resources, including independent explanation of the benefits and challenges of different decision making practices, and customisable template agreements. This should include resources specifically designed to meet the needs of people with disabilities, such as in various communication formats, multimedia and technology. (For instance, Advocacy for Inclusion recently launched our Supported Decision Making App – a learning and support tool that employs tablet and smartphone technology to step people through the process of making a decision.)

This hub should provide expert training and clear independent explanatory information. Staff would need to be experienced communicators and well-trained in presenting options in an unbiased unpressured style. The hub should not privilege or promote one particular style or method of supported decision making, but rather should encourage customisation and innovation to ensure people can receive decision making support in a way that suits their needs and preferences.

**Recommendation 29:** The ACT should develop a central repository of accessible unbiased information about the various options for supported decision making.

**Recommendation 30:** Staff at the SDM hub must have considerable expertise in communication and training in order to provide independent explanation, advice and support to people with disabilities.

There will often be indicators that a person is needing support as they interact with various service systems, for instance a health professional or community worker may notice that a person is expressing fear or uncertainty about making particular decisions, or identify a specific risk factor, such as the person experiencing unmanaged health problems or intimate partner violence. People with disabilities who are experiencing violence, neglect or abuse are often isolated or unaware of their rights and entitlements, or of available supports, or how to request or access them.\(^\text{106}\) This may be a particular risk for people with some form of communication impairment or those living in institutionalised settings. There is potential to redesign and strengthen the current mechanisms for the observations or concerns of frontline personnel to prompt the provision of relevant information, guidance and support to assist the individual to access available services or remedies. This should include an independent and accessible explanation to the individual about their decision making rights and supported decision making options.

Specific training may be needed to ensure people working (or volunteering) in frontline roles become skilled at identifying or interpreting any requests or other expressions that indicate the person is needing information and support about decision making. The focus of this training must be on identifying those people who may need support and how to refer the person to independent information, and the support to access and understand options for receiving support in decision making.

**Recommendation 31:** Frontline personnel must receive training in recognising when a person should be referred to (and given support to access) independent information about their decision making rights and the different ways they may choose to receive support to make decisions.

The *Guidelines* do not permit concerned professionals or well-meaning community members to make their own (unaccountable) assessment of what kind of decision making support a person requires or on imposing the support that is believed “best” for the individual. Therefore, training must stress that any apprehensions of a person needing support (and subsequent referrals being made to information, training, or support) does not permit any prejudicial treatment from the legal system, for instance in the continuing legal presumption that the

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person has the ability to make their own decisions, which is expressed in Guidelines for assessing support needs, clause a.

When an individual desires specific recognition and documentation of their chosen supported decision arrangements, they should have access to a mechanism (such as through application to the tribunal, or an optional registration process) to grant their arrangement formalised recognition. This process should be an accessible one, with minimal bureaucratic complexity. Recognition must not impede flexibility in the ongoing arrangements between the person requiring decision making support and their supporters. Nor must it remove or compromise the freedom of individuals to change their arrangements or choose to no longer receive support to make decisions.

**Recommendation 32:** Police officers, social workers and other first responders must be trained to recognise persons with disabilities as full persons before the law. This entails training and awareness-raising in these important professions.

**Recommendation 33:** A person who requires decision making support and who wishes to formalise this through specific legal recognition should have access to a flexible and supportive process through which to achieve this.

**Recommendation 34:** A person must remain free to direct, and initiate changes to, how they are supported to make decisions.

**Supporter duties**

Priority must be placed on ensuring that informal decision-making relationships are acknowledged and supported by legislation and legal processes. The wishes of the person with disability to have their chosen supporters, informal or formal, involved in decisions should be enshrined in law. The lack of recognition of supported decision making in law has been a major barrier to decision making rights of people with disabilities. While supporting the formal acknowledgement of supported decision making in legislation, we share the concern raised by various other stakeholders about over formalising supported decision making.

As supported decision making is an arrangement chosen by the individual, it is they who must direct how they wish to be supported in decision making. The parameters of a supporter’s role and duties must be determined by the person. However, this should not preclude a person accessing and using resources and advice in choosing how they wish the supporter to deliver decision making support. If a person wishes to formalise their arrangements in an agreement, a template that prompts a person to consider what duties they would like the supporter to accept and fulfill, and for instance, what records the supporter should keep, would be very useful in setting the terms of the relationship.

**Recommendation 35:** Specific resources should be developed to assist a person needing decision making support to decide what duties and role they would like their chosen supporter to accept and fulfill.

The point of supported decision making is to promote the decision making rights of people with disabilities. Over-formalising supported decision making contradicts this point by not trusting people with disabilities to informally manage their own arrangements, with access to safeguards and monitoring as they see necessary.

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107 This section responds to question 5.2 of the Response Booklet: "What evidence should a supporter be required to keep to show that they provided support to help the person make a decision? Should this vary with different types of decisions?"
By over-formalising supported decision-making, the process becomes dehumanised and bureaucratised. What should be a regular daily process cannot occur without permissions or appointments. Research literature suggests that people with disabilities are made vulnerable by this “othering”, where the person with disability is not seen as “one of us” and their decision processes inherently different to that of the general community.

Through this the general community disconnects and becomes less able to empathise with people with disabilities. For example, the impersonal and dehumanised nature of disability service settings is seen as a key factor in the high rates of violence in institutional settings, including small group homes. Regardless of how supportive and personalised a service provider sets out to be, the very nature of the “paid” formal service setting is inherently disempowering and depersonalising. When a person has access to adequate natural relationships, wherein they are respected and valued, these relationships safeguard against the risk of exploitation and violence. People in natural support relationships experience less violence and abuse than people in paid service setting. For similar reasons, ideally the majority of supported decision making arrangements should be informal.

By over-regulating supported decision making there is also the risk of hindering the autonomy and decision making rights of people with disabilities. It takes away their control by potentially setting out how decision making arrangements should operate, who they could appoint as a supporter, and what the supporter might be obliged to do. This should all remain at the discretion of the person with disability with access to safeguards and monitoring if they choose.

There will be cases where a person with disability does not have access to respectful, trusting, natural relationships. In these cases, if the person with disability chooses they should be supported to establish relationships with formal supporters who have undergone appropriate checks, and who have undertaken training in supported decision making. Supported decision making should be considered a mostly informal arrangement, while representative decision making should be considered a formal arrangement.

Recommendation 36: Where a person with disability does not have existing appropriate natural relationships for a supported decision making arrangement, they should have access to formal supporters who have undergone appropriate checks and training so that they can select a person they are comfortable with.

Guidelines for Giving Effect to Will, Preferences and Rights

The CRPD General Comment on Article 12 explains:

Where, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the “best interpretation of will and preferences” must replace the “best interests” determinations. This respects the rights, will and preferences of the individual, in accordance with article 12, paragraph 4.

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112 This section responds to question 5.1 of the Response Booklet: “What do you think about the Australian Law Reform Commission’s Guidelines for Giving Effect to Will, preferences and Rights? Do you think they are useful? Is there anything else that should be there?”


http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx
Representative decision making should only be used when the person with disability’s current will and preference cannot be ascertained, after all steps to ascertain them have been tried. The person with disability is still regarded as having legal capacity with decision making authority; however, as their will and preference cannot be ascertained a representative is required to interpret the person’s will and preference based on available information. Representative decision making should be limited in scope, be proportionate and apply for a specific minimum time.

**Recommendation 37:** Representative decision making should be considered a formal model of decision making, which requires independent monitoring and safeguards to maximise transparency and accountability.

Representative decision making must not be contingent upon a subjective assessment of a person’s decision making capacity. Rather it would be used only when a person’s will and preference pertaining to a particular decision cannot be ascertained by any means.

This model can be distinguished from the general understanding of substitute decision making because the person with disability retains their legal capacity. They are regarded as having the right to make their own decisions. However their decision — their will and preference — cannot be ascertained even after all efforts, including decision making support, have been undertaken. The person’s legal capacity is given effect, by a representative who considers the persons will and preferences and human rights, rather than “best interests”.

It is also different to supported decision making where the person’s current will and preferences are known and the person is supported to actively and directly make their own decision.

On the rare occasions when it is determined that representative decision making is required, all efforts to ascertain the person’s current will and preferences must continue to be made by the representative throughout the decision making process using a strict framework. Ascertaining the person’s current will and preference must be viewed as an ongoing process, not simply part of determining whether representative decision making is required.

Advocacy for Inclusion remains concerned that representative decision making could result in people with disabilities having decisions made on their behalf when they are able to make and express in some form their own decisions. This is because of the current culture surrounding decision making for people with disabilities, whereby they are considered unable and not entitled to make their own decisions. As is currently the case with guardianship practices, we are concerned that a representative decision making model is at real risk of being overused and indeed that substitute decision making principles and practices will pervade both supported and representative decision making arrangements. Therefore, support for cultural change and the provision of monitoring and safeguards will be critical.

**When does a person need a representative to be appointed to make decisions for them?**

To comply with the expectations of Article 12, representative decision making must only have a very narrow application. Any person who is able to convey their will and preference through any means of communication should be considered able to make their own decision, even if the person needs support to understand and weigh information pertaining to the decision. This approach shifts emphasis toward supporting a person with disability to make decisions rather than subjectively assess their decision making capacity.

Representative decision making should be used only as a last resort when the person’s current will and preferences are completely unable to be ascertained, and where a decision is required in order for the person

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114 This section responds to question 8.2 of the Response Booklet: “How can we know what level of support a person needs, and when they need it?”
to access their human rights. We envisage that this model would be applied rarely and affect very few people in very specific circumstances. An example of a circumstance where representative decision making might be required is when a person is comatose.

In our submission to the ALRC, we suggested a framework for determining whether representative decision making is required:

1. The person’s will and preference cannot be ascertained even after all efforts have been made to communicate with that person and support that person to express their will and preference.

2. All efforts to ascertain a person’s will and preference include at least the following steps:
   
   a. The person is supported to receive information and communicate their will and preferences pertaining to the relevant decision using all forms of information and communication appropriate to the person. This includes using unconventional communication formats such as computer technology and respect for the person’s cultural and linguistic circumstances.
   
   b. Communication and decision support is attempted by the person’s significant others, including people with whom the person has existing familiar and trusting relationships and any existing formal or informal decision-supporters appointed by the person.
   
   c. Where the person does not have such relationships, the person is supported to establish relationships with volunteers with the potential to act as decision-supporters.
   
   d. Information is provided and communication attempted by other parties who might be involved in the relevant decision.
   
   e. As much time as possible is allowed for the person to undertake the steps above.

Where a person with disability’s current will and preference cannot be ascertained, after all steps to ascertain them have been tried, representative decision making would provide a last resort to ensure the person’s human rights are protected. Rather than subjective notions of the person’s “best interests” guiding the representative, respect for the person’s human rights, and particularly the right to freedom from harm, including violence, abuse, and neglect would inform any decision made. The Guidelines on Representative Decision Making include:

- A representative may override the person’s will and preferences only where necessary to prevent harm.

Representatives should not be appointed where a person’s will and preferences are able to be ascertained. This Guideline would therefore have extremely narrow application in situations where a person has had a representative appointed who continues to be unable to determine the person’s will and preferences, and a decision needs to be made to avoid harm (for instance to consent to vital medical treatment). If the person were to recover the ability to express their will and preferences, the representative must be able to defend the decision made by pointing to their initial efforts to determine the will and preferences, through consulting others and gathering information, and their subsequent default to a human rights framework, demonstrating the reasoning on which the decision made was based.

Appointment representatives

In those situations in which it is necessary for a representative to be appointed to make decisions for an adult, natural supports who are familiar with the person’s history, who are well-positioned to determine what that individual would likely want and who do not have any conflict of interest should be appointed, if available.

Currently, the Public Guardian is appointed to act as “guardian of last resort” when there is no-one else willing or suitable to take on this role. It is concerning that Public Guardians usually have very high caseloads and

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may struggle to gather information. Public Guardians effectively act as administrators of decisions, rather than people who form genuine relationships with a person, and who can offer support to help a person with disability to make their own decisions. They are generally not in a position to have an informed idea of the person’s expressed wishes. Yet, they can and do make life changing decisions on the person’s behalf.

The preferred model would drastically reduce the need for professionals to act in this role of making decisions on a person’s behalf. Any representative who is appointed must have the opportunity to gather information and consult with family members, carers and other significant people to ensure the decisions made are directed by the best interpretation of the individual’s likely will and preferences and with reference to their human rights. Sufficient resourcing must be provided for this to occur, whether that role continues to be taken by an adjusted version of the Public Guardian or by other appropriate, independent bodies who are knowledgeable of the decision making guidelines and are driven by human rights. This would include trustworthy community organisations.

Recommendation 38: The following framework should be used to provide guidance on when a representative needs to be appointed:

1. The person’s will and preference cannot be ascertained even after all efforts have been made to communicate with that person and support that person to express their will and preference.

2. All efforts to ascertain a person’s will and preference include at least the following steps:
   a. The person is supported to receive information and communicate their will and preferences pertaining to the relevant decision using all forms of information and communication appropriate to the person. This includes using unconventional communication formats such as computer technology and respect for the person’s cultural and linguistic circumstances.
   b. Communication and decision support is attempted by the person’s significant others, including people with whom the person has existing familiar and trusting relationships and any existing formal or informal decision-supporters appointed by the person.
   c. Where the person does not have such relationships, the person is supported to establish relationships with volunteers with the potential to act as decision-supporters.
   d. Information is provided and communication attempted by other parties who might be involved in the relevant decision.
   e. As much time as possible is allowed for the person to undertake the steps above.

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115 In March 2015, Senior Guardian/Advocate Sue Houghton explained to the Joint Standing Committee on the NDIS the involvement of Public Guardian ACT in progressing NDIS plans and service agreements for this group of participants: “In our office over the 24-month period of the trial, we have identified that 88 of our current clients will be eligible to access NDIS assistance. One-third of our clients will transition in the last quarter, the last phase, which will be a huge impost on our workload… (It is) very difficult sometimes….to ensure that every single element of care for an individual is included in their plan. It is very difficult.” Ms Houghton giving evidence before the Joint Standing Committee on the National Disability Insurance Scheme (2015) Public Hearing (Official Hansard) Office of the Public Guardian in Western Australia has also cited the volume of work and the “rocky path” of gathering information as ongoing challenges. Bev Turner (2012) Responding to Community Concerns about Vulnerable Adults, Presented at the Second World Congress on Adult Guardianship, 15 October 2012. Melbourne. Slide 18.
Determining what the person would likely want

Examples of information that might be used to interpret the person’s will and preference includes previous decisions made by the person throughout their life, any relevant directions previously given by the person, and current expressions of communication. They could be used to interpret what the person's will and preferences might be. In a representative decision making arrangement, any relevant directives made by the person in advance would be given effect. In many cases the existence of relevant advance directives would negate the need for representatives to be appointed.

The person’s human rights would also inform the decision making process in addition to interpretation of the person's will and preference. If the people consulted disagree about what the person would want and there is conflicting information, the representative should evaluate these sources in a rational manner and look to a human rights framework if extra guidance is needed to resolve the dilemma.

Where the representative is not confident of their interpretation of the person’s likely will and preference, or of how to promote the person’s human rights they should consult human rights experts for guidance.

Recommendation 39: The use of advance directives should be encouraged and promoted to the ACT population.

Recommendation 40: Representatives must have access to human rights expertise as needed.

Representative duties and decision review

Representative decision making should be considered a formal model of decision making, which requires independent monitoring and safeguards. Transparency and accountability measures would be critical to ensure power is not abused, that the person’s will and preferences are being respected, and that all efforts to ascertain the person’s will and preferences are regularly being undertaken. This is important as the person with disability is not actively expressing her own decisions and therefore does not have the opportunity to seek out or choose if offered to access monitoring and safeguards at that point in time.

Representatives should be expected to provide more extensive documentation and considered justification for decisions that are of greater significance and involve multiple human rights. As discussed above, efforts to ascertain the person’s current will and preferences must continue to be made by the representative throughout the decision making process using the framework outlined. Ascertaining the person’s current will and preference must be viewed as an ongoing process that continues after a representative has been appointed.

Recommendation 41: Ascertain the person with disability’s current will and preference must be viewed as an ongoing part of the representative decision making process. All efforts to ascertain the person’s current will and preferences must continue.

Recommendation 42: An appointed representative must keep records to evidence how they have fulfilled and adhered to the Principles and Guidelines in making a decision for a person.

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116 This section responds to question 5.4 of the Response Booklet: “How will a representative work out what the person would likely want when the person is unconscious or otherwise unable to communicate their wishes and preferences?”

117 Current expressions of communication in these circumstances would provide no overt direction pertaining to the decision because they should otherwise be considered the person’s direct will and preferences.

118 This section responds to questions 5.3, 5.4, 5.5 and 8.2 of the Response Booklet.
Discretionary standards

Although, the shift to supported decision making will return the majority of decisions to the control of people with disabilities, the reformed legal framework and processes will necessarily continue to require (or allow) the exercise of judicial or administrative discretion on the rare occasions when someone is completely unable to express their will and preferences. For instance the Tribunal may be required to determine whether all possible support (including using alternative means of communication) has been provided to a person to express their will and preferences regardless of their level of consciousness, before appointing a representative, or whether a representative who has been appointed to make a decision has consulted all relevant people and information in determining what the person would likely want.

In drafting legislation and designing procedures and policies, the ACT must avoid using the language or structures that particularly encourage or allow for paternalistic, value-laden determinations that are premised on or apply any of the outdated notions discussed above. These include the medical model of disability, the “best interests” of the person, inherent “vulnerability”, risk avoidance, and traditional understandings of legal capacity and decision making. New legislation cannot by itself overcome old attitudes. To speed up the desired ideological and cultural change, training and awareness raising will also be required.

In an article on legislative style, Lawrence M. Solan has posited that it is difficult to write good guardianship laws – meaning legislation that effectively regulates judicial discretion and is also sufficiently flexible - because “we expect too much of them”, and that some legislatures “resort to drafting broad statutes whose standards are simply too low to reduce discretion sufficiently”.

Solan underlined the importance of:

> legislators and policy makers [becoming] aware that these are actual choices, and that their underlying sets of values and concerns should drive which style to use in a particular law

Recommendation 43: The ACT must ensure legal professionals, government officials, ACAT officers and the Public Guardian are fully trained in Article 12 and the principles and practice of supported decision making, and kept informed of all aspects of the legislative, procedural and policy reforms.

Recommendation 44: Legislation, procedures and policy frameworks must be worded using contemporary human rights language and concepts, and structured with clarity and focus, in order to limit the system’s reliance on judicial and administrative discretion. These arrangements must be deliberately crafted to minimise the potential for paternalism or other discriminatory attitudes to influence any determinations made regarding the lives and decisions of people with disabilities.

Safeguards and accountability

In relation to the respective duties of supporters and representatives, the person will have chosen their supporter/s whereas a representative is appointed for them. Therefore, representatives must have mandated accountability measures, as this is an intervention imposed upon the person that must be subject to appeal, monitoring and review. Supported arrangements should be kept informal where the person needing decision making support wishes, and if they choose they should be able to access to external monitoring and statutory supports to keep their supporters in check.

People with disabilities in supported and representative decision-making arrangements should have access to the safeguards similar to those outlined in the ALRC’s proposal:

- Guidelines on decision supporter duties;

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120 Ibid.
121 This section responds to questions 5.5 and 6 of the Response Booklet.

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• Affirming the person with disability as the decision maker with the right to revoke the appointment of a
decision supporter at any time;
• Recognising multiple decision supporters where the person with disability has appointed more than one
supporter (formally or informally);
• The provision of culturally appropriate guidance and training to people who require decision-making
support, supporters and departments interacting with supporters.

Additionally, people with disabilities should have access to an independent body set up to monitor and provide
safeguards to people with disabilities in supported and representative decision making arrangements.

People with disabilities in supported decision making arrangements should have the opportunity to access
safeguards and monitoring resources as they choose (with support as needed). Representative decision
making should be considered a formal arrangement, automatically subject to independent monitoring and
safeguards. This is highly important in terms of transparency and accountability. A significant power imbalance
would be present in any representative decision making arrangement as the person with disability’s direct will
and preferences are not known. Thorough and frequent transparency and accountability measures exercised
by an independent body will be critical in safeguarding against misuse of power.

The ACAT could move to undertake these monitoring responsibilities given that they will have far fewer orders
to make under a supported decision making system, and they have existing independent statutory status.

Where concerns for the wellbeing of a person with disability arise, for example concerns about violence or
exploitation, the person with disability should be provided with the social, emotional, physical, practical and
decision-making support to find safety. Many people without cognitive impairment find themselves in unsafe,
unhealthy situations and relationships. Everyone is entitled to make their own decisions about how to respond
to such circumstances, with appropriate support. It is pertinent not to further traumatis and remove control
from a person who is being abused by taking away their decision-making authority. Support and
encouragement for that person is the best way to protect their rights and wellbeing.

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.\footnote{South Australian Office of the Public Advocate, Op Cit.} It is all the more reason we need reformed legislation that realistically responds to
these grey areas.

Recommendation 45: The ACAT to provide formal monitoring and safeguards for people with
disabilities in supported and representative decision making arrangements.

Recommendation 46: ACACT monitoring must be a non-negotiable feature of representative decision
making, whilst people in supported decision making arrangements may access this resource by
choice (with support as needed).

Redefining “safety” and “protection”

A lack of control and choice is at the core of the issues experienced by people who come to Advocacy for
Inclusion. This powerlessness poses the biggest risk to the wellbeing and safety of people with disabilities in

\footnote{South Australian Office of the Public Advocate, Op Cit.}

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their support arrangements, and their capacity to reach their potential and contribute to society. The move away from guardianship will enhance the control people with disabilities have over their lives, and give them more choice, and the opportunity to build decision making skills. This will lead to fewer people with disabilities being isolated, exposed to high levels of risk, or made vulnerable by the social and cultural environment and will ultimately result in people living safer lives.

Self-determination is a key protective factor for all people. It can be supported through independent community based disability advocacy, increased oversight and accountability, and accessible remedies and complaints mechanisms. Control and choice cannot be achieved through regulating people with disabilities with paternalistic and controlling policies and structures. Safeguarding frameworks should be focused on enhancing meaningful and tangible support for people with disabilities to exercise self-determination, coupled with robust accountability, transparency and monitoring systems for service providers.

**Guidelines for Safeguards**

It is critical that conflicts of interests are minimised to the greatest extent possible in any supported decision-making arrangement. The ALRC has noted that there may be circumstances where it is appropriate for a paid person to perform duties as a decision supporter, including paid carers. Advocacy for Inclusion suggests that it might be appropriate for independent advocacy organisations (organisations independent from other services and supports provided to people with disabilities) to provide decision support within their paid roles if the person with disability so chooses.

However, where a person is provided decision support by a paid carer/ worker there are pre-existing and major conflicts of interest. Regardless, a person with disability should be entitled to appoint decision supporters as they choose in recognition that they are equal decision makers. Easily accessible independent monitoring mechanisms should be available to any person with disability in supported decision making arrangements.

In cases of representative decision making, paid workers providing essential services (such as support workers, case workers or health professionals) must not be appointed as decision representatives. Independent community advocacy organisations would not be appropriate either as such services should be available to people with disabilities to independently assist them with any issues in their facilitated decision making arrangements; however, the appointment of an independent advocate to monitor and question representatives would be appropriate.

**Recommendation 47:** People with disabilities in supported decision making arrangements should be entitled to appoint anyone they choose (who is willing and able) to be their decision supporter.

**Recommendation 48:** People with disabilities should have access to an independent body providing monitoring and safeguards to assist them to manage any potential conflicts of interest as they choose.

**Recommendation 49:** Paid workers providing essential services (such as support workers, case workers, paid advocates or health professionals) must not be appointed as representatives in order to minimise conflicts of interest.

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123 This sub-section responds to question 6 of the Response Booklet: “What (do) you think about the Australian Law Reform Commission’s Guidelines for Safeguards. Do you think they are useful? Is there anything else that should be there?”

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Supported decision making arrangements should be determined by the person with disability, with support as needed, and never imposed upon the person. Everyone has different support and learning needs. People should be able to access resources and information about different ways of engaging in supported decision making and be supported to understand, evaluate and select methods or strategies that would best suit them. A person with disability might wish to formalise or retain informality and flexibility, and they may prefer to establish a relationship with one trust individual or involve several people. Australian and overseas examples that could provide inspiration have been discussed in ‘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’.

Providing opportunities for people to learn and develop their skills will be critical. People with disabilities cannot be expected to easily slide into supported decision making arrangements, knowing their rights and feeling confident to take control and make choices. The current system has conditioned and institutionalised them not to make choices and not to take control over the decisions concerning their own lives. Likewise, support people and carers have been taught that people with disabilities do not know their own best interests and that they need others to make decisions on their behalf.

People with disabilities and their support networks need assistance to learn new habits and to develop a new culture around decision making in a new system. Bach found in his study on people with disabilities who transitioned to an individualised funding model that many did not gain control or choice over their support. Service providers and support people continued to control the funds, as they had prior to the new model. Some people with disabilities were not even aware that they had individualised funding. When it comes to guardianship, it is likely that similar patterns will emerge without cultural change. It is highly important that people with disabilities and their supporters also have access to training and support to make supported decision-making arrangements successful and to help them transition to a new paradigm of decision-making.

While government will need to be supportive by providing services, funding and community scope; supported decision making is primarily an activity concerning the community. The community sector will be integral to challenging stereotypes and distributing information necessary to promote the use of supported decision making. Partnerships between the independent community sector and government agencies will be essential to ensure responsibility, independence and access.

**Recommendation 50:** The ACT must invest in sufficiently resourcing supported decision making training and support for people with disabilities and their decision supporters to facilitate cultural change. This includes training and support regarding decision making rights for people with disabilities, supported decision making principles and practices, and changes in legislation.

**Recommendation 51:** The ACT must resource the community sector to train people with disabilities and their supporters on using supported decision making successfully in the long term.

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124 This section responds to questions 7, 9, 10 and 11 of the Response Booklet.
Attitudinal barriers

Implementing supported decision making and moving towards a community that is more inclusive for people with disabilities necessitates attitudinal change. Attitudinal change is complex to measure and manage.\textsuperscript{129} 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 the changes will have their intended impact. Without change to assumptions, beliefs and structures currently surrounding disability, these reforms could fall short of their potential.\textsuperscript{130}

To some, supported decision making may seem like a radical shift. 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 long term success of supported decision making. Improving community and individual attitudes has often been considered a function of community and individual interaction with people on whom discriminatory attitudes or stereotypes are placed.\textsuperscript{131} \textsuperscript{132} Studies have found that it is in interaction over the long term on equal grounds that attitudinal change is most prominent.\textsuperscript{133} 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.

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 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 training.\textsuperscript{134}

Supported decision making values training and the role of supporters, guardians and family. It is likely that some work will also need to be done to facilitate situations where a person seeks the guidance of a supporter who is not in their immediate or current circle of support, or where there are no natural supports to provide decision support.\textsuperscript{135} 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.

Ensuring cultural change

Experience in Canada has not only demonstrated the need for cultural change to support legislation for supported decision making, 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.\textsuperscript{136} 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.

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\textsuperscript{129} 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,

\textsuperscript{130} O’Brien, J., 1999, Community Engagement: A necessary Condition for Self-determination & Individual Funding, Responsive Systems Association

\textsuperscript{131} 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,

\textsuperscript{132} Thompson, et. al. Op. Cit.

\textsuperscript{133} 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,

\textsuperscript{134} Advocacy for Inclusion, Op. Cit.

\textsuperscript{135} Nicholson, C., 4 April 2012, Decision making – South Australian Project, Presentation, DANA Conference, Australian Capital Territory.


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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.\(^{137}\)

It should be noted that in other jurisdictions legislative change does not always equate to cultural change.\(^{138}\) 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, 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.\(^{139}\)

Recommendation 52: 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.

Recommendation 53: The ACT to fund the development of a program for families and supporters who may be involved in supported decision making. The emphasis should be on valuing skills, talents and interests. This should be co-designed with people with disabilities.\(^{140}\)


\(^{140}\) Ibid.

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Conclusion

The ACT should aim to be at the forefront of international expectations in its reforms to adult decision making arrangements. As a human rights jurisdiction the ACT must seize the current review opportunity to lead the way in implementing supported decision-making models and embracing the paradigm shift expected by Article 12.

The ACT should take a leadership role in the development of a nationally consistent approach to implementing Article 12 and the use of supported decision making. Reforms must be driven and informed by strong commitment to Article 12 and a true understanding of its meaning and the obligations it compels.

Existing guardianship laws are incompatible with Article 12 as clarified the UN Committee in its 2014 General Comment – implementation requires “the abolition of substitute decision-making regimes”. The Committee recommended that Australia replace substitute decision making with supported decision making.

Guardianship compounds vulnerability, it does not negate it. Guardianship orders necessitate an imbalance of power, unequal access to legal assistance and uneven valuing of knowledge in both procedure and outcome. The perception that guardianship protects and cares for people with disabilities is unrealistic and must be challenged.

Self-determination is a key protective factor for all people. It can be supported through independent community based disability advocacy, increased oversight and accountability, and accessible remedies and complaints mechanisms. Control and choice cannot be achieved through regulating people with disabilities with paternalistic and controlling policies and structures. Safeguarding frameworks should be focused on enhancing meaningful and tangible support for people with disabilities to exercise self-determination, coupled with robust accountability, transparency and monitoring systems for service providers.

Advocacy for Inclusion envisions adults with disabilities in our community exercising their decision making rights, with the support they need to do so. This vision requires law reform driven by and committed to the rights of people with disabilities to self-determination, equal recognition before the law and equal enjoyment of legal capacity.

The successful implementation of Article 12 will require coordinated reforms to other areas of law. Consistent and supportive measures to drive cultural attitudinal change across all policy areas and sectors will be integral to this success. Considerable investment will be needed to ensure the provision of appropriate support and training is available to people with disabilities, family members, carers and support workers and to personnel across relevant statutory agencies, professions services sectors and industries.

Advocacy for Inclusion appreciates the opportunity to contribute to this review process. We look forward to further engaging with the Committee and other stakeholders.