

advocacy for **inclusion**

Submission to ALRC Inquiry: Equality, Capacity and Disability in Commonwealth Laws

Advocacy for Inclusion

July 2014

About Advocacy for Inclusion

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

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

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

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

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Recommendations

1. That the ALRC recommend the government resource 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.
2. That the ALRC refrain from recommending a “fully supported” decision-making model. This model is a form of substitute decision-making, which cannot safeguard the rights of people with disabilities. Substitute decision-making diminishes, rather than protects, the rights of people with disabilities.
3. The four high level National Decision-Making principles are commendable.
4. Everybody has the right to make decisions, regardless of their assessed (perceived) decision-making capacity. This idea is reflected in the ALRC’s proposed Decision-Making Principle 1 and must continue to be reflected throughout the ALRC’s recommendations.
5. The ALRC should *not* view the proposed “fully supported” decision-making model as a true supported decision-making model. Any model that does not regard the person with disability as the decision maker cannot be considered a supported decision-making model.
6. The ALRC should consider that 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. If a person expresses their will and preference through any means, this should be respected regardless of whether they are assessed as having impaired decision-making capacity.
7. Where a person with disability’s *current* will and preference cannot be ascertained, after all steps to ascertain them have been tried, facilitated decision-making should be used.
8. Facilitated decision-making should be considered a formal model of decision-making, which requires independent monitoring and safeguards to maximise transparency and accountability.
9. The following could be considered in the development of a framework for determining whether facilitated 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.

10. Ascertaining the person with disability's *current* will and preference must be viewed as an *ongoing* part of the facilitated decision-making process. After it is apparent that facilitated decision-making is required, all efforts to ascertain the person's *current* will and preferences must continue.
11. The priority for the ALRC should be to ensure that informal supported decision-making arrangements are acknowledged and supported by Commonwealth, State and Territory laws. The wishes of the person with disability to have their chosen supporters, informal or formal, involved in decisions should be enshrined in law.
12. 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.
13. An independent body should be established to provide formal monitoring and safeguards for people with disabilities in supported and facilitated decision-making arrangements. This should be a non-negotiable feature of facilitated decision-making, whilst people in supported decision-making arrangements should access this resource by choice (with support as needed).
14. 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. They should have access to an independent body providing monitoring and safeguards to assist them to manage any potential conflicts of interest as they choose.
15. In cases of facilitated decision-making paid workers providing essential services (such as support workers, case workers, paid advocates or health professionals) must *not* be appointed as decision facilitators in order to minimise conflicts of interest.
16. The ALRC should make further recommendations about how Section 13 of the *Evidence Act* could be significantly reworked. Where a person is able to make their views known through any means pertaining to a question about the fact this should be recognised and the person properly supported to understand and respond to the question.
17. Where a person is able to make their views known via any means of communication they should be entitled to vote. They should be entitled to do so with appropriate social and technological supports. Entitlement to vote should not depend upon a subjective assessment of decision-making capacity.

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. Working alongside people with disabilities subject to guardianship orders or applications for guardianship orders comprises a major part of our direct individual advocacy work. Our submission is informed by our experience providing this direct advocacy support to people with disabilities.

The ALRC's Discussion Paper provides a thorough analysis of the legal and practice issues regarding equal recognition before the law and legal capacity of people with disabilities. It includes a number of progressive proposals. The four National Decision-Making Principles proposed are commendable, especially Decision-Making Principle 1, the right to make decisions. This could promote an important shift away from the current preoccupation with assessment of decision-making capacity towards acknowledgement of decision-making rights.

However, Advocacy for Inclusion is concerned that there remains a heavy focus on the decision-making *capacity* instead of decision-making *rights* of people with disabilities in the ALRC's paper. The concept of "fully supported" decision-making is particularly problematic and does not reflect the universality of legal capacity, explained in CRPD General Comment on Article:

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.¹ (emphasis added)

The ALRC should include a stronger emphasis on making recommendations that will lead to legislative recognition of informal, natural supported decision-making arrangements. A stronger focus on the need for cultural change is also required in order to support societal transition towards a new decision-making paradigm for people with disabilities in accordance with Australia's obligations under Article 12 of the CRPD.

The need for cultural change

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 need protection from themselves and from society. Guardianship practices are a product of this culture and major cultural change is needed to address it. As the ALRC has outlined, current guardianship laws include measures to promote the person's autonomy. This includes restricting guardianship for use only as a last resort. The person's will and preference is also included as an important component of acting in the person's best interests.

However, direct individual advocacy experience tells us that in practice 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. Where a person's wishes are ascertained, they bear little weight. Our consumers and people with disabilities involved in our studies tell us that they are not given a chance to voice their wishes, or when they are they are not viewed as having authority.^{2 3}

¹ CRPD Committee. (2014). *Article 12: Equal recognition before the law*. Paragraph 8. <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>

² 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>

³ Advocacy for Inclusion. (2012). *Supported decision-making, legal capacity and guardianship*. http://www.advocacyforinclusion.org/images/Publications/Decision_Making/supported_decision_making_legal_capacity_and_guardianship2012final.doc

“[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.”⁴

In the ACT the Tribunal has ceased granting plenary orders. However, in practice guardians and involved parties assume that the guardian has the right and responsibility to make decisions concerning any area of the person with disability’s life. It is not common practice for service providers, professionals and support workers 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.

In our experience service providers assume that if a person has any cognitive limitation or even any disability they need a guardian to make decisions for them. Guardianship is seen as a solution to the person’s problems.⁵ In some cases service providers push relentlessly for their consumers to be put on guardianship orders for administrative and risk management purposes.

Substitute decision-making practices are likely to be used in supported decision-making arrangements due to this surrounding culture. We are particularly concerned that the proposed “fully supported” decision-making model would become the default replacement for guardianship practices (this model is discussed further below). For this reason, we encourage the ALRC to make further recommendations to promote cultural change.

Regarding the transition to the NDIS the Productivity Commission asserted that:

against an historical background of lack of choice and control, substantial capacity building and support will be required for many people with disabilities and their families.⁶

Bach⁷ 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. Cultural change is therefore 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.

Existing ALRC Proposals include 4-11 and 4-12 aimed at equipping those involved or interacting with supported decision-making arrangements. 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.

Recommendation 1: That the ALRC recommend the government resource supported decision-making training and support for people with disabilities and their decision supporters to facilitate cultural

⁴ Advocacy for Inclusion. (2012). *Supported decision-making, legal capacity and guardianship*.

http://www.advocacyforinclusion.org/images/Publications/Decision_Making/supported_decision_making_legal_capacity_and_guardianship2012final.doc

⁵ Advocacy for Inclusion. (2012). As above.

⁶ Productivity Commission. (2011). *Disability Care and Support*. Report no. 54, Canberra.

⁷ Bach, M. (2000). *Individualised funding and self-determination: making sure the means does not become the end*. The Roeher Institute. Presented at the First International Conference on Self-determination and Individualized Funding

change. This includes training and support regarding decision-making rights for people with disabilities, supported decision-making principles and practices, and changes in legislation.

Decision-making and vulnerability

There are no cases in which substitute decision-making is needed or indeed is able to protect the rights of people with disabilities. The “fully supported” decision-making model proposed by the ALRC is a form of substitute decision-making (explored in the sections below) and is unable to protect the rights of people with disabilities.

It is increasingly recognised among academics and activists that people with disabilities are not inherently vulnerable through personal attributes such as cognitive or physical impairment. People with disabilities are made vulnerable through the social and cultural environment. People with disabilities 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.^{8 9 10 11 12 13 14} People with disabilities often do not have access to the supports they need to exercise their rights and have their views and concerns acknowledged.

Part of the problem is the 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 very own lives. This makes people with disabilities vulnerable and marginalised. For example, 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.

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 traumatise 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. A decision-making model for circumstances where the person’s will and preference cannot be ascertained is discussed below.

For these reasons, substitute and “fully supported” decision-making regimes do not protect people with disabilities. Rather they make them more vulnerable by reinforcing the idea that the views and concerns of people with disabilities are unreliable and invalid.

Recommendation 2: That the ALRC refrain from recommending a “fully supported” decision-making model. This model is a form of substitute decision-making, which cannot safeguard the rights of people with disabilities. Substitute decision-making diminishes, rather than protects, the rights of people with disabilities.

⁸ Scope & Deakin University. (2013). *Australians fail social inclusion test for people with a disability*.

<http://ahha.asn.au/news/australians-fail-social-inclusion-test-people-disability>

⁹ Australian Bureau of Statistics. (2011). Labour force. 4446.0 – Disability, Australia, 2009.

¹⁰ OECD. (2010). *Sickness, Disability and Work: Breaking the Barriers - A Synthesis of Findings across OECD Countries*.

Appendix K The disability support pension. Productivity Commission Inquiry Report. No. 54, 31 July 2011

¹¹ Walsh, J. (2012). Australia’s health 2012: Social inequalities, health inequalities. Retrieved from www.aihw.gov.au

¹² OECD. (2009). *Sickness, disability and work: Keeping on track in the economic downturn – Background paper*.

¹³ Australian Bureau of Statistics. (2011). Education. 4446.0 – Disability, Australia, 2009.

¹⁴ Hughes, K., Bellis, M. A., Jones, L., Wood, S., Bates, G., Eckley, B., McCoy, E., Mikton, C., Shakespeare, T., & Officer, A. (2012). Prevalence and risk of violence against adults with disabilities: A systematic review and meta-analysis of observational studies. *Lancet*, 379, 1621-29

Decision-Making Principle 1 – The right to make decisions

Any person who is able to in some way 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.

Advocacy for Inclusion commends the four high level principles proposed by the ALRC. In particular, the shift in focus brought by Principle 1 toward decision rights rather than capacity is highly important. It is consistent with the General Comment on CRPD Article 12, which asserts:

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.¹⁵

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. The CRPD General Comment on Article 12 explains:

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.¹⁶

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. Any models that allow the denial of a person's legal capacity on the basis of their assessed decision-making capacity are not compliant with CRPD Article 12. Beginning with the principle that all persons have the right to make decisions is a helpful shift towards recognising the universality of legal capacity.

The ALRC proposes that an assessment of capacity is at times inescapable and outlines a framework for determining whether a person has the ability to make decisions about their own lives. The ALRC's assertion that any such assessment "should be seen as much further along a spectrum, with the focus being squarely on supporting decisions, rather than assessing whether or not a person can make a decision" (p. 63) is progressive. However, the concepts of "fully supported" decision-making and "representative" decision makers outlined in the ALRC's paper are inconsistent with Decision-Making Principle 1 and with Article 12 of the CRPD (discussed below).

Furthermore, given the current culture surrounding decision-making for people with disabilities, the preoccupation with measuring a person's decision-making capacity will continue for some years to come. There is already a presumption of capacity across Guardianship laws, yet this has not deterred a cultural focus on assessing the capacity of a person with disability.

Recommendation 3: The four high level National Decision-Making principles are commendable.

Recommendation 4: Everybody has the right to make decisions, regardless of their assessed (perceived) decision-making capacity. This idea is reflected in the ALRC's proposed Decision-Making Principle 1 and must continue to be reflected throughout the ALRC's recommendations.

¹⁵ CRPD Committee. (2014). *Article 12: Equal recognition before the law*. Paragraph 33. <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>

¹⁶ CRPD Committee. (2014). *Article 12: Equal recognition before the law*. Paragraph 14. <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>

Fully supported decision-making

Any model that does not regard the person with disability as the decision maker cannot be considered a supported decision-making model. 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. Advocacy for Inclusion cannot see how the “fully supported” decision-making model proposed by the ALRC could operate any differently in practice to current substitute decision-making practices, especially as they can be imposed on a person with disability based on subjective assessments of decision-making capacity.

If a person expresses their will and preference through any means, this should be respected regardless of whether they are assessed as having impaired decision-making capacity. The person makes a decision 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.

In cases where a person’s will and preference cannot be ascertained, the term “fully supported” decision-making is wrong because the current will and preference of the person with disability is unknown, and therefore they are not actively making a decision. The model proposed by the ALRC also allows a person to be considered as having no legal capacity. 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.¹⁷ (emphasis added)

Therefore, legal capacity cannot be removed from a person under any circumstances. The most important difference between substitute and supported decision-making is not the different application of “best interests” and “will and preferences” approaches, although these are significant. The key difference is who is recognised as having decision-making authority; in other words “legal capacity”.

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.

Recommendation 5: The ALRC should *not* view the proposed “fully supported” decision-making model as a true supported decision-making model. Any model that does not regard the person with disability as the decision maker cannot be considered a supported decision-making model.

Recommendation 6: The ALRC should consider that 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. If a person expresses their will and preference through any means, this should be respected regardless of whether they are assessed as having impaired decision-making capacity.

¹⁷ CRPD Committee. (2014). *Article 12: Equal recognition before the law*. Paragraph 8. <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>

Facilitated decision-making

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 4.¹⁸

For these circumstances, PWDA, ACDL and AHRCentre suggest a model of decision-making in their joint submission¹⁹ to the CRPD Draft General Comment on Article 12. They refer to this model as “facilitated” decision-making²⁰.

Facilitated decision-making would 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 decision facilitator is required to interpret the person’s will and preference based on available information. Facilitated decision-making should be limited in scope, be proportionate and apply for the minimum time, as suggested by the ALRC in regards to “fully supported” decision-making.

This model is different to the “fully supported” decision-making model proposed because it is not 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.

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. 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. They could be used to interpret what the person’s will and preferences *might* be. In a facilitated decision-making arrangement, any relevant directives made by the person in advance would be given to effect.

The person’s human rights would also inform the decision-making process in addition to interpretation of the person’s will and preference.

This model is also different to 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 decision facilitators, who consider 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.

Facilitated decision-making would 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 to access

¹⁸CRPD Committee. (2014). *Article 12: Equal recognition before the law*. Paragraph 21.

<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>

¹⁹ PWDA, ACDL & AHRCentre. (2014). *Submission to the CRPD Draft General Comment on Article 12 of the Convention: Equal recognition before the law*. http://webcache.googleusercontent.com/search?q=cache:http://www.pwd.org.au/documents/pubs/SB-140221-CRPDArticle_12.pdf

²⁰ Not to be confused with “facilitated *communication*”

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 facilitated decision-making might be required is when a person is comatose.

Facilitated 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 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.

Advocacy for Inclusion suggests the following could be considered in the development of a framework for determining whether facilitated 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.

When it is apparent that facilitated decision-making is required, all efforts to ascertain the person's *current* will and preferences must continue to be made by decision facilitator/s throughout the decision-making process using the framework above. Ascertaining the person's *current* will and preference must be viewed as an *ongoing* process of facilitated decision-making, not simply part of determining whether facilitated decision-making is required.

It is important to note Advocacy for Inclusion remains concerned that a facilitated decision-making model 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 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 facilitated decision-making model is at real risk of being overused and indeed that substitute decision-making principles and practices will pervade both supported and facilitated decision-making arrangements. Support for cultural change and the provision of monitoring and safeguards (discussed below) would therefore be critical.

Recommendation 7: Where a person with disability's *current* will and preference cannot be ascertained, after all steps to ascertain them have been tried, facilitated decision-making should be used.

Recommendation 8: Facilitated decision-making should be considered a formal model of decision-making, which requires independent monitoring and safeguards to maximise transparency and accountability.

Recommendation 9: The following could be considered in the development of a framework for determining whether facilitated 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.

Recommendation 10: Ascertaining the person with disability's *current* will and preference must be viewed as an ongoing part of the facilitated decision-making process. After it is apparent that facilitated decision-making is required, all efforts to ascertain the person's *current* will and preferences must continue.

Formalising supported decision-making

The priority for the ALRC should be to ensure that informal decision-making relationships are acknowledged and supported by Commonwealth and State and Territory laws. 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 is a major barrier to decision-making rights of people with disabilities. For this reason we support the idea of formally acknowledging supported decision-making in legislation. However, we share the concern raised among other stakeholders about over-formalising supported decision-making.

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.

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.^{21 22 23} 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.²⁴ 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 the appropriate checks, and who have undertaken training in supported decision-making. Supported decision-making should be considered a mostly informal arrangement, while facilitated decision-making should be considered a formal arrangement.

Recommendation 11: The priority for the ALRC should be to ensure that informal supported decision-making arrangements are acknowledged and supported by Commonwealth and State and Territory laws. The wishes of the person with disability to have their chosen supporters, informal or formal, involved in decisions should be enshrined in law.

Recommendation 12: 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.

Monitoring and safeguards

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

- Guidelines on decision supporter duties;
- 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.

²¹ Fitzsimons, N. M. (2009). *Combating violence and abuse of people with disabilities: A call to action*. Maryland, USA: Paul H. Brookes Publishing Co.

²² Hollomotz, A. (2011). *Learning difficulties and sexual vulnerability: A social approach*. London: Jessica Kingsley Publishers.

²³ Sobsey, D. (1994). *Violence and abuse in the lives of people with disabilities: The end of silent acceptance?* USA, Maryland: Paul H. Brookes Publishing Co.

²⁴ 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>

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 facilitated 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). Facilitated 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 facilitated 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 would be critical in safeguarding against misuse of power.

Recommendation 13: An independent body should be established to provide formal monitoring and safeguards for people with disabilities in supported and facilitated decision-making arrangements. This should be a non-negotiable feature of facilitated decision-making, whilst people in supported decision-making arrangements should access this resource by choice (with support as needed).

Conflicts of interest

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 of 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. Easily accessible independent monitoring mechanisms should be available to any person with disability in supported decision-making arrangements (outlined above).

In cases of facilitated decision-making, paid workers providing essential services (such as support workers, case workers or health professionals) should *not* be appointed as decision facilitators. 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.

Recommendation 14: 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. They 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 15: In cases of facilitated decision-making paid workers providing essential services (such as support workers, case workers, paid advocates or health professionals) must *not* be appointed as decision facilitators in order to minimise conflicts of interest.

Legislative recognition of supported and facilitated decision-making

In the context of the suggestions outlined in this submission, Advocacy for Inclusion supports amendments to various Commonwealth and state and territory Acts in order to promote compliance with CRPD Article 12 and consistency with the ALRC's proposed decision-making principles. We also support the proposal for the Australian Banker's Association to issue guidelines reflecting the National Decision-Making Principles.

Access to justice – Giving evidence

Advocacy for Inclusion supports proposals 7-9, 7-10 and 7-11. We suggest that the ALRC should make further recommendations about how Section 13 of the *Evidence Act* could be significantly reworked to better reflect the proposed National Decision-Making Principles. Section 13 does not seem to reflect proposed Principle 1: the right to make decisions. If a person is able to make their views known through any means pertaining to a question about the fact this should be recognised. The scrutiny should be upon whether the person is being adequately supported to understand the question, including whether the question was delivered in formats most appropriate to the person's understanding, rather than upon determining the person's capacity to understand.

Recommendation 16: The ALRC should make further recommendations about how Section 13 of the *Evidence Act* could be significantly reworked. Where a person is able to make their views known through any means pertaining to a question about the fact this should be recognised and the person properly supported to understand and respond to the question.

Restrictive practices

Advocacy for Inclusion supports Proposal 8-1.

Entitlement to vote

Where a person is able to make their views known via any means of communication they should be entitled to vote. They should be entitled to do so with appropriate social and technological supports. Entitlement to vote should not depend upon a subjective assessment of decision-making capacity.

Where an enrolled elector objects that a person can make their views known, an independent party should be responsible for verifying/not verifying that the person's views cannot be ascertained via any means of communication. This should be done at each time the person's duty to vote arises. This independent party should be a representative from an independent monitoring body available to people with disabilities in supported or facilitated decision-making arrangements, suggested above. The representative should be experienced and skilled in communicating with people with disabilities who use a wide range of alternative communication formats.

Advocacy for Inclusion supports Proposals 9-5 and 9-5 in the context of our suggestions made above. The electoral commission should also provide support to people with disabilities to cast votes. Many people with disabilities are isolated and have minimal natural trusting relationships. People with disabilities should have the option to access support by an electoral officer to cast their vote, subject to safeguards and monitoring. If it is clear who they wish to vote for then the electoral officer should assist them.

Recommendation 17: Where a person is able to make their views known via any means of communication they should be entitled to vote. They should be entitled to do so with appropriate social and technological supports. Entitlement to vote should not depend upon a subjective assessment of decision-making capacity.

Conclusion

The ALRC's Discussion Paper provides a thorough analysis of the legal and practice issues regarding equal recognition before the law and legal capacity of people with disabilities. It includes a number of progressive proposals. The four National Decision-Making Principles proposed are commendable, especially Decision-Making Principle 1, the right to make decisions. This could promote an important shift away from the current preoccupation with assessment of decision-making capacity towards acknowledgement of decision-making rights.

However, Advocacy for Inclusion is concerned that there remains a heavy focus on the decision-making *capacity* instead of decision-making rights of people with disabilities in the ALRC's paper. The concept of "fully supported" decision-making is utterly problematic. The ALRC should include a stronger emphasis on making recommendations that will lead to legislative recognition of informal, natural supported decision-making arrangements. A stronger focus on the need for cultural change is also required in order to support societal transition towards a new decision-making paradigm for people with disabilities.

Advocacy for Inclusion thanks the ALRC for undertaking this major and important inquiry. It has been a privilege to be involved in the Inquiry and to contribute our experience and expertise on decision-making. We look forward to the final recommendations.