

# **Office of the Public Advocate (Qld) Systems Advocacy**

## **Submission to the Australian Law Reform Commission**

Equality, Capacity and Disability in  
Commonwealth Laws Discussion Paper

**June 2014**

## Introduction

This submission focuses on two aspects of the Australian Law Reform (ALRC) Discussion Paper *Equality, Capacity and Disability in Commonwealth Laws* (the ‘Discussion Paper’):

- the proposed national decision-making principles; and
- the proposed Commonwealth decision-making framework.

## Background

### Interest of the Public Advocate (Qld)

The Public Advocate was established by the *Guardianship and Administration Act 2000* (Qld) to undertake systems advocacy on behalf of adults with impaired decision-making capacity in Queensland. The primary role of the Public Advocate is to promote and protect the rights, autonomy and participation of Queensland adults with impaired decision-making capacity in all aspects of community life.

More specifically, the functions of the Public Advocate are:

- promoting and protecting the rights of adults with impaired capacity;
- promoting the protection of the adults from neglect, exploitation or abuse;
- encouraging the development of programs to help the adults reach their greatest practicable degree of autonomy;
- promoting the provision of services and facilities for the adults; and
- monitoring and reviewing the delivery of services and facilities to the adults.<sup>1</sup>

In 2014, there are approximately 113,000 Queensland adults with impaired decision-making capacity.<sup>2</sup> Of these vulnerable people, most have a mental illness (54 per cent) or intellectual disability (26 per cent).

Queensland adults with impaired decision-making capacity are among the most disadvantaged people in the community. An unacceptably high level of disadvantage is experienced across a range of social and economic indicators. This disadvantage significantly reduces quality of life and increases the risk of abuse, neglect and exploitation. The disadvantage experienced by adults with impaired decision-making capacity is by no means unique to Queensland.

### The decision-making regime in Queensland

The **current decision-making regime in Queensland** provides for a range of advance, informal and formal decision-makers.

In Queensland, guardianship legislation comprises the ***Guardianship and Administration Act 2000* and the *Powers of Attorney Act 1998***.

The *Powers of Attorney Act 1998* allows adults to make decisions and/or arrangements that can be implemented in the future if they lose capacity, including provision for advance health directives and enduring powers of attorneys. Where an adult does not have capacity and has not made arrangements under the *Powers of Attorney Act 1998*, the *Guardianship and Administration Act 2000* provides a system by which people can, either formally or informally, act as a decision-maker for that adult.

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<sup>1</sup> *Guardianship and Administration Act 2000* (Qld) s 209.

<sup>2</sup> Office of the Public Advocate (Queensland), *The Potential Population for Systems Advocacy*, Fact Sheet (February 2013).

The *Guardianship and Administration Act 2000* recognises that decisions for an adult can be made informally by the adult's existing support network,<sup>3</sup> which may include members of the adult's family, close friends of the adult, and other people recognised by the Queensland Civil and Administrative Tribunal as providers of support to the adult.<sup>4</sup> There is also provision for the Tribunal to ratify or approve a decision of an informal decision-maker, which may be of value in situations where there is doubt about the appropriateness of a decision or if ratification is required by a third party.<sup>5</sup>

The *Guardianship and Administration Act 2000* and *Powers of Attorney Act 1998* are underpinned by **general principles** that must be applied by any person or entity who performs a function or exercises a power under these Acts.

Of particular note is **Principle 2 (Same human rights)**, which requires that all adults, regardless of capacity, are accorded the same basic human rights. The importance of empowering an adult to exercise these rights must also be recognised and taken into account.<sup>6</sup>

**Principle 7 (Maximum participation, minimal limitations and substituted judgement)** builds on the above principle by preserving the right of people to be involved in decisions about their own lives to the greatest extent possible, and specifies that 'any necessary support' must be provided to enable a person to be involved in their own decision-making.<sup>7</sup>

The *Guardianship and Administration Act 2000* also imposes obligations to: act in a manner that is the **least restrictive of a person's autonomy**; **provide decision-making support** to allow a **person's views and wishes to be sought and given effect**; and endeavour to **involve members of a person's existing support network** in decision-making processes.<sup>8</sup>

The principles that underpin the *Guardianship and Administration Act 2000* and the *Powers of Attorney Act 1998*, in particular principles 2 and 7 broadly align with the paradigm shift declared by the *United Nations Convention on the Rights of Persons with Disabilities* ('the Convention'), reflecting a shift in focus from what a person cannot do to the supports that should be provided to enable people to make decisions and exercise their legal capacity.

While the general principles form a rights-based foundation for the Acts, the Office of the Public Advocate is nonetheless aware of the high rates of guardianship in Queensland and a number of barriers to the full implementation of the general principles in the guardianship legislation. In light of this, the Office has commenced **a research project to explore the systemic barriers and enablers to protecting and supporting the right of a person to make their own decisions**. The research is exploring this within the context of Queensland's public guardianship system, with a view to identifying opportunities to enhance Queensland's decision-making regime for people who may need support to make decisions.

As part of our research information is being gathered through a series of interviews, surveys and group discussions with the Queensland Civil and Administrative Tribunal, Office of the Adult Guardian and the Public Trustee. The Public Advocate will also invite submissions on this issue from stakeholders and the broader community.

The research will inform discussion in Queensland about how to strengthen its decision-making regime and the decision-making support provided to people who are deemed to have impaired capacity. It is also likely to identify issues requiring further investigation.

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<sup>3</sup> *Guardianship and Administration Act 2000* (Qld) s 9(2)(a).

<sup>4</sup> *Guardianship and Administration Act 2000* (Qld) sch 4 (definition of 'support network').

<sup>5</sup> *Guardianship and Administration Act 2000* (Qld) s 154.

<sup>6</sup> *Guardianship and Administration Act 2000* (Qld) sch 1 pt 1. s 2.

<sup>7</sup> *Guardianship and Administration Act 2000* (Qld) sch 1 pt 1. s 7.

<sup>8</sup> *Guardianship and Administration Act 2000* (Qld) sch 1 pt 1. ss 5, 7.

## Overall position of the Public Advocate (Qld)

While some form of substitute decision-making will be needed in the foreseeable future, there is considerable work to be done to reduce the current over-reliance on state-based guardianship systems and to encourage the use of other supportive mechanisms for people to continue making their own decisions.

People's decision-making capacity and autonomy should be preserved, and reliance on formal appointments of substitute decision-makers reduced as far as possible. This may be achieved through a number of key initiatives:

- **greater promotion of advance planning mechanisms**, including education and advice on their benefits and how to make advance health directives and enduring documents;
- **greater involvement and formal recognition of family, friends, carers** and others providing support and assistance to people to make their own decisions; and
- **enhanced and more coordinated access to the support and other services** that people with disability need, including much greater case-management support.

The last point will be crucial under the National Disability Insurance Scheme (NDIS). Without a multi-layered strategy as outlined above, as well as much needed further work aligning the state-based and Commonwealth decision-making arrangements, including the nominee scheme under the *National Disability Insurance Scheme Act 2013* (the 'NDIS Act'), the implementation of the **NDIS has the potential to:**

- **increase the demand for and reliance on state-based guardianship systems**, given that there are numerous points in the system where decisions must be made;
- **leave many people with decision-makers** (such as nominees) making decisions on their behalf **without adequate safeguards**, monitoring and oversight; and
- **create confusion, duplication and possible conflict** between multiple decision-makers appointed under state-based guardianship schemes and Commonwealth nominee schemes.

The **rights-based approach** proposed by the Discussion Paper has great potential for people with disability and is consistent with the paradigm shift in the Convention. There are also many potential benefits associated with the Commonwealth decision-making regime proposed in the Discussion Paper such as formal recognition for supporters with third-party agencies (which should reduce the need for substitute decision-maker appointments); an enhanced focus on supporting a person to make their own decisions (rather than decisions being made on their behalf); and encouragement of the close involvement of family, friends and supporters in a person's life (which can also be a significant safeguard).

Legislation alone however will not drive the cultural, policy and practice changes that are needed to ensure a rights-based approach is implemented in a way that is beneficial to people with disability. High order principles such as 'acting in a way to promote and safeguard the person's rights' can (like the best-interests test) be just as vulnerable to implementation in an unprincipled way with a lack of transparency, where decision-makers use their own discretion to decide what best promotes and safeguards a person's rights. A rigorous and robust legislative framework with criteria to be applied is important, along with **education, training, communication, advocacy and monitoring**.

There should be an **over-arching goal to reduce the reliance on formally appointed substitute decision-makers and truly realise the goal of 'last resort' guardians** and administrators for people who may need decision-making support. To this end, the Office is concerned that some aspects of the proposed Commonwealth decision-making regime may **duplicate the current state based decision-making regimes and potentially create conflict with existing state-based schemes**. Given that the Commonwealth only legislates in some areas of social services that people with disability might require, many people will still approach tribunals for guardianship and administration orders; prepare and execute enduring documents; make advance directives; and receive informal supports.

Having two schemes operating (state-based schemes and Commonwealth schemes) is likely to add to the over-complicated service system for people with disability, their family and carers. It is also likely to create confusion for third-party agencies and entities (such as financial institutions and utilities providers) about who they can deal with.

Finally, **the provision of safeguards is critically important.** At present, both the NDIS nominee scheme and the proposed representative scheme (under the Commonwealth decision-making model) potentially lack sufficient safeguards. The issue of the potential overuse and over-reliance on guardianship and administration, which affects people's rights to make decisions, should not be confused with the important safeguards that are also provided by the state-based guardianship regimes. These include, for example, the oversight and independent review provided by the existing tribunals and the protective and investigative role played by Adult/Public Guardians, Public Advocates and community visitor programs.

## Detailed response

### National Decision-Making Principles

The national decision-making principles proposed by the Discussion Paper represent a significant opportunity to lead the incorporation of the paradigm change brought about by the Convention into Australia's domestic laws, policies and programs. A national and consistent approach to setting the agenda and driving change in this area is welcome and supported.

#### Proposed national decision-making principles

1. Every adult has the right to make decisions that affect their life and to have those decisions respected.
2. Persons who may require support in decision-making must be provided with 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. Decisions, arrangements and interventions for persons who may require decision-making support must respect their human rights.<sup>9</sup>

The proposed principles are similar to the current principles and underlying objectives of Queensland's *Guardianship and Administration Act 2000*, with the exception of the rights-based approach usurping the primacy of the best-interests approach.

There are four key issues relating to the proposed decision-making principles that require consideration:

- a **rights-based approach** to decision-making support must be carefully implemented in legislation and effectively supported with education, advocacy and communication strategies to ensure consistency, transparency and accountability in decision-making practices;
- the **right to support for people with disability** must not just involve the encouragement and formal recognition of informal support, but also the provision of enhanced and more coordinated social services, including better case management;
- the **principled implementation of a least restrictive approach**; and
- **consideration of capacity (or ability) needs to move beyond a binary approach** to accommodate the formal recognition of supporters.

<sup>9</sup> Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* (Discussion Paper 81) Proposal 3-1.

## A rights-based approach to decision-making support

The emphasis on a rights-based approach to the actual provision of decision-making support to people with disability in the Discussion Paper is important.

Principles three and four emphasise supported decision-making approaches that are driven by the person's will, preferences and human rights.

The proposed guidelines for representative decision-makers (where a representative decision-maker is appointed as a last resort) provide for an approach to decision-making where rights are the crucial backdrop so that:

- A person's will and preferences, so far as they can be determined, must be given effect;
- Where the person's will and preferences are not known, the representative must give effect to what the person would likely want, based on all the information available, including communicating with supporters; and
- If it is not possible to determine what the person would likely want, the representative must act to promote and safeguard the person's human rights and act in the way least restrictive of those rights.<sup>10</sup>

While it is important to ensure that people with disability are protected from abuse, neglect and exploitation, and that their support needs are met in a way that ensures their optimal mental, physical and social well-being, a best-interests approach has unfortunately not always delivered this outcome. There exists a concern that a rights-based approach may similarly fail to deliver upon its intended outcomes.

In some ways, poor outcomes resulting from the best interests approach can be attributed to the history of the development of the approach under the *parens patriae* jurisdiction. It is a jurisdiction that was principally guided by its paternalistic exercise with respect to children, and the state's increasingly interventionist role in this regard.<sup>11</sup>

A best interests approach has also been poorly understood and implemented. For example, what is in a person's best interests has often been conflated with 'medical judgement' or another professional's judgement. Such determinations do not take into account the particular views, wishes and needs of the person.<sup>12</sup>

'Best interests' is often applied in an unsystematic way without any unpacking of relevant considerations, including the values and principles applied in the decision-making process. This is illustrated in the following comment by Professor Ian Kennedy about the borrowing of this approach from the family law jurisdiction:

*The best interests approach of family law allows the courts to atomise the law, to claim that each case depends on its own facts. The court can then respond intuitively to each case while seeking to legitimate its conclusion by asserting that it is derived from the general principle contained in the best interests formula. In fact, of course, there is no general principle other than the empty rhetoric of best interests; or rather, there is some principle (or principles) but the court is not telling. Obviously, the court must be following some principles, otherwise a toss of a coin could decide cases. But these principles, which serve as pointers to what amounts to the best interests, are not articulated by the court. Only the conclusion is set out. The opportunity for reasoned analysis and scrutiny is lost.*<sup>13</sup>

<sup>10</sup> Ibid 60.

<sup>11</sup> *Re Eve* 31 DLR (4th) Forest J [1986].

<sup>12</sup> House of Lords Select Committee on the *Mental Capacity Act 2005*, *Mental Capacity Act 2005: Post-Legislative Scrutiny* (House of Lords Paper 139, 2014).

<sup>13</sup> Ian Kennedy 'Patients, Doctors and Human Rights' in Robert Blackburn and John Taylor (eds), *Human Rights for the 1990s: Legal, Political and Ethical Issues* (Mansell, London, 1991).

Similarly Brennan J, in his dissenting judgement in *Marion's Case* emphasised that 'the best interests approach offers no hierarchy of values which might guide the exercise of a discretionary power'.<sup>14</sup>

Without careful guidance, education, training and advice, a rights-based approach could be similarly fraught. The kind of cultural change that needs to be achieved will be difficult to affect without a holistic strategy. In the House of Lords' review of the United Kingdom's *Mental Capacity Act 2005* (an Act which contains many similar principles to proposed National Decision-Making Principles and the guidelines for representative decision-makers), it was found that while in the main the Act was held in high regard, it suffered from a lack of awareness and a lack of understanding. The House of Lords Select Committee commented that:

*...the prevailing cultures of paternalism (in health) and risk-aversion (in social care) have prevented the Act from becoming widely known or embedded. The empowering ethos has not been delivered. The rights conferred by the Act have not been widely realised. The duties imposed by the Act are not widely followed.*<sup>15</sup>

To mitigate against this, supporters and other decision-makers must be provided with guidance about how to apply a rights-based approach, including how to evaluate and weigh different considerations. Formal guidelines or codes of practice under the relevant legislation should also be provided to guide decision-makers in implementing a rights-based approach.

Such an approach has emerged in the United Kingdom, where courts have moved towards a more systematic application of the best interests approach. Beginning for example with the approach taken in *Re A (Medical Treatment: Male Sterilisation)*,<sup>16</sup> where Dame Butler Sloss P distanced the best interests approach from reliance on medical judgement and professional duty of care, and rather noted the relevance of a human rights standard. Thorpe LJ utilised a balance sheet approach, setting out the benefits to be gained on one side, the 'dis-benefits' on the other as well as an assessment of the possibility of the gain or loss accruing. This approach also has a constructive way of managing risk, which might be more congruent with a dignity of risk approach, and less prone to paternalism. This is alluded to by Thorpe LJ in the following statement from *Re A*:

*At the end of that exercise the judge should be better placed to strike a balance between the sum of the certain and possible gains against the sum of the certain and possible losses. Obviously only if the account is in relatively significant credit will the judge conclude that the application is likely to advance the best interests of the claimant.*

*I suggest this approach only because Sumner J's judgment in the present case seems to me to concentrate too much on the evaluation of risks of happenings, some of which seem to me at best hypothetical. A risk is no more than a possibility of loss and should have no more emphasis in the exercise than the evaluation of the possibility of gain.*<sup>17</sup>

This approach was later formulised in a *Practice Note (Declaratory Proceedings: Medical and Welfare Decisions for Adults Who Lack Capacity)*.<sup>18</sup>

It is important that a rights-based approach is exercised in similarly transparent and value-based way by representative decision-makers. Otherwise, like the best-interests test, it too could be open to misuse and abuse.

## **The right to support for people with disability**

Principles one and two adopt the rights-based approach of the Convention and emphasise the positive onus on state parties to ensure adequate support is provided. However, the right to support must incorporate a number of elements, not just the promotion and recognition of a person's informal support networks.

<sup>14</sup> *Department of Health and Community Services v JWB & JWB & SMB (Marion's Case)* [1992] HCA 15 (1992) 175 CLR 218.

<sup>15</sup> House of Lords Select Committee on the Mental Capacity Act 2005, above n 12, 6.

<sup>16</sup> *Re A (Medical Treatment: Male Sterilisation)* [2000] 1 FCR 193.

<sup>17</sup> *Ibid* 206 (Thorpe LJ).

<sup>18</sup> Mary Donnelly, *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge, 2010) 181.

Apart from the recognition that people with disability also needed lawful authorisations for a range of decisions, the increasing complexity of social services systems was a key societal change prompting the development of all State and Territory guardianship regimes.

This need to negotiate the labyrinth of social services continues to drive appointments of substitute decision-makers today. One of the key ways in which people's decision making capacity can be protected and preserved (and pressure on state guardianship systems can be reduced) is for the State and Commonwealth governments to provide enhanced (including more coordinated) access to social services. People with disability, their families, carers and supporters must be supported to navigate the array of social services they need without disempowering or disenfranchising them.

The provision of this support should be a particular focus of the NDIS and any proposed reforms to the relevant Commonwealth laws. The lack of funded and appropriate assistance to apply to become a NDIS participant and develop and review a participant's plan is likely to result in a need for further appointments of substitute decision makers, particularly where a person does not have available family, friends or supporters to assist them, or their family and supporters are similarly overwhelmed.

Agencies that provide social services have a positive onus placed upon them to make their services accessible to people with disability, including people with intellectual impairment.

The provision of this accommodation and assistance is part of the reasonable adjustments and accommodations that support services should make, and for this reason the principle should be actively applied to these agencies and incorporated into anti-discrimination law.

### **Principled implementation of a least restrictive approach**

The proposed safeguards guidelines are designed to capture the essential elements of that should be incorporated into Commonwealth laws and legal frameworks about decision-making support.

#### **Safeguard Guidelines**

Laws and legal frameworks must contain appropriate safeguards in relation to decisions and interventions in relation to persons who may require decision-making support to ensure that such decisions and interventions are:

- a) the least restrictive of the person's human rights
- b) subject to appeal and
- c) subject to regular, independent and impartial monitoring and review.<sup>19</sup>

The ALRC has sought input on how best to express the '**least restrictive**' safeguard guideline, consistent with a human rights approach and the supported decision-making approach proposed in the Discussion Paper.

Within a human rights framework there can be justification for limiting rights, but only those non-derogable rights. Some rights, such as freedom from torture or arbitrary arrest and detention, cannot be limited. Some rights may be limited for example to protect the person and others from harm. When rights are limited it is important that:

- there is a clear legal basis for the limitation, and that it has sufficient precision/specificity and precise criteria;<sup>20</sup>
- there should not be unfettered discretion provided to those charged with limiting people's rights;<sup>21</sup>

<sup>19</sup> Australian Law Reform Commission, above n 9, 71.

<sup>20</sup> *Coco v R* [1994] HCA 15 [10]; *Attorney-General (SA) v Corporation of the City of Adelaide* [2013] HCA 3 [42].

<sup>21</sup> UN Human Rights Committee, General Comment No 27 (1999), paragraph 13.



- the restriction is specific to the reason it is being curtailed, necessary and proportionate;<sup>22</sup> and
- the limitation is only applied in exceptional circumstances.<sup>23</sup>

The principle of proportionality is central to the least restrictive criterion. It requires a precise balancing of the intensity of a measure with the specific reason for interference.<sup>24</sup>

In summary, what is important is open and transparent criteria and a principled approach. This is equally important when applying a rights-based approach.

### **Consideration of capacity (or ability) when appointing supporters**

The Discussion Paper redefines capacity as ‘ability’ and represents the threshold for ability in line with a functional rather than a status based assessment.

Any determinations about a person’s decision-making ability and any appointment of a representative decision-maker should be informed by the following guidelines:

- a) An adult must be presumed to have ability to make decisions that affect their life.
- b) A person has ability to make a decision if they are able to:
  - understand the information relevant to the decision and the effect of the decision;
  - retain the information to the extent necessary to make the decision;
  - use or weigh that information as part of the process of making the decision; and
  - communicate the decision.
- c) A person must not be assumed to lack decision-making ability on the basis of having a disability.
- d) A person’s decision-making ability will depend on the kinds of decision to be made.
- e) A person’s decision-making ability may evolve or fluctuate over time.<sup>25</sup>

It is acknowledged that determinations of capacity (or ability) will continue to be important in law for a wide range of matters (for example entering into a binding contract, disposing of property by will or gift, voting, becoming a member of parliament, holding various public offices, in some states having sexual relations with another person, marrying, authorising many forms of medical treatment, and engaging in various occupations).<sup>26</sup>

As noted by many commentators, determination of capacity or otherwise is the current gatekeeper to a person retaining their decision-making rights.<sup>27</sup> In the past, these determinations have tended to be ‘status based’; that is, based on whether the person has a certain condition or disability. There is now a much greater acceptance of the ‘functional approach’ to capacity, where the focus is less on whether a person has capacity in general and instead on whether a person has capacity to make a specific decision.<sup>28</sup>

While this shift is a welcome change, this can also lend itself to a binary and an absolutist approach. Capacity has traditionally been viewed by the law as a deterministic and absolute concept. A person either has capacity or they do not; and if they do not have capacity then this disqualifies them from making a range of decisions.

There is a growing emphasis on strength-based assessments for capacity, where capacity should be

<sup>22</sup> UN Human Rights Committee, General Comment No.22 (1993), paragraph 14.

<sup>23</sup> UN Human Rights Committee, General Comment No 10 (1993), paragraph 4.

<sup>24</sup> Australian Human Rights Commission, *Lawful Limits on Fundamental Freedoms (Human Rights (Brief No 4, 2006))*; Manfred Nowak, UN Covenant on Civil and Political Rights: CCPR Commentary, NP Engel, 1993, 379.

<sup>25</sup> Australian Law Reform Commission, above n 9, 61.

<sup>26</sup> Victorian Law Reform Commission, *Guardianship: Final Report (Report No 24 2012)*, 100.

<sup>27</sup> Donnelly, above n 18, 90.

<sup>28</sup> Ibid 93.

related less to the level of a person’s cognitive capacity or functional ability and more to the level of support that is available to a person, or that could be built around the person to enable them to make the decision.

To that end, it would seem unfortunate to continue with a binary and deterministic threshold. The concept that someone has capacity to make decisions if they are provided with support could also be given legal recognition. In fact, this type of approach may be needed to accompany the legal recognition of and threshold for the appointment of supporters.

Such an approach however would need to be accompanied by strong safeguards to guard against the risk of undue influence, abuse and exploitation.

## Proposed commonwealth decision-making regime

This part outlines the:

- **potential benefits** of the proposed Commonwealth decision-making model; and
- **potential disadvantages** of the proposed Commonwealth decision-making model.

The proposed Commonwealth decision-making regime, underpinned by the proposed national decision-making principles, incorporates a number of elements including:

- The incorporation of a new role of ‘**supporters**’ in Commonwealth legislation, who are appointed by a person who may require decision-making support to enable them to make a decision;
- The incorporation of a new role of ‘**representatives**’ in Commonwealth legislation, who are appointed for a person who requires ‘full decision-making support’ to assist the person to make decisions.<sup>29</sup>

The role of **supporters** as outlined in the Discussion Paper is to provide support to people who may require decision-making support to enable them to make a decision but will otherwise retain their decision-making power and responsibility. Supporters may be an individual or organisation and will be empowered under legislation to:

- assist the person to make decisions and provide advice;
- handle, obtain and communicate relevant personal information relating to the person; and
- communicate or assist the person to communicate their decisions.<sup>30</sup>

The role of the **representative** as outlined in the Discussion Paper is for those people who require ‘full support’ in decision-making. Appointed as a last resort, the representative role is very similar to a substitute decision-maker except that:

- it is described as ‘fully supported’ decision-making; and
- where a person’s wishes and preferences cannot be ascertained, a representative makes a decision not ultimately guided by the person’s best interests, but so as to promote and safeguard the person’s human rights and act in the way least restrictive of those rights.

A representative would most likely be appointed by an independent court or tribunal (or alternatively an agency head) and would be subject to regular reviews by a court or tribunal.

### Potential benefits

Presently many people with disability receive informal support to make decisions, but for a number of reasons that are unrelated to a ‘lack of capacity’ to make decisions with support, the appointment of a formal substitute decision-maker is sought.

<sup>29</sup> Australian Law Reform Commission, Equality, above n 9, Proposals 4-3 and 4-6.

<sup>30</sup> Ibid 85.

Anecdotally at least, one of the key issues that may lead to the appointment of formal substitute decision-makers is that supporters of people with disability have great difficulty dealing with, including getting information from and communicating with, third parties on behalf of a person. Financial institutions, phone companies, hospitals and health services will often refuse to talk to or provide information to supporters of people with disability. In many such situations, the appointment of a formal decision-maker may address this problem.

Another impetus for the appointment of substitute decision-makers is to fulfil administrative requirements demanded by agencies. In Queensland, it has been reported to the Office of the Public Advocate that many aged care services will not admit a person unless that person has an advance health directive AND a guardian, administrator or attorney. Hospitals will also often seek appointments to facilitate the conduct of Aged Care Assessment Team assessments or admission to an aged care facility.

When a person with disability turns 18 years of age, their parents must often seek appointment as their guardian to carry on the informal supportive role that they have been performing with their son or daughter, again to satisfy third party requirements. Of particular concern in such situations is that, once a substitute decision maker is appointed for a particular matter, the person can no longer legally make decisions with respect to that matter.

The legal recognition of ‘supporters’ potentially addresses many of these problems. It may mean that a person with disability can continue to receive informal support to make decisions and communicate with third parties, without the need for their legal decision-making capacity to be revoked. Accompanied by a system of education, advocacy, training, advice and safeguards, encouraging an informal network of supporters in a person’s life can have therapeutic, capacity building and safeguarding benefits.

### **Potential disadvantages or issues**

The two greatest concerns with the proposed Commonwealth decision-making model are:

- the potential for the Commonwealth regime to duplicate and conflict with state-based decision-making schemes; and
- the lack of safeguards, particularly associated with the proposed representative decision-makers including NDIS nominees.

### **Supporters**

In many instances, supporters who wish to communicate with and obtain information on behalf of people with disability will require legislative authority to do so. Ideally, Commonwealth legislation should recognise the role of supporters and authorise the sharing of such information. What lawmakers must be cognisant of is that, whilst it is likely that a person will have a limited number of supporters, those supporters will be liaising with a wide range of entities and agencies. Some of these entities or agencies will be outside of the Commonwealth legislative purview.

The proposed scheme, as outlined in the Discussion Paper, would mean that supporters would have to be appointed under a multitude of different legislative frameworks; potentially with different duties, obligations and possible reporting requirements associated with each. The confusion and responsibility associated with such a scheme may deter or prevent supporters from being appointed to such a role. Further, supporters would still need authority to deal with a range of agencies not subject to the Commonwealth legislation.

In some cases, despite the existence of a supporter appointed under a number of Commonwealth Acts, the state-based guardianship tribunal may appoint a substitute decision-maker such as a guardian for a matter for which a supporter is also appointed. This may create conflict and ambiguity for the person and the support agency about who should provide support, obtain personal information and make decisions in a given situation.

It is therefore more logical to have a system of central registration or appointment. The legislative

frameworks of state based decision-making regimes are an obvious vehicle for this. This would enable state-based guardianship and tribunal systems to have a central record of people's appointed supporters to avoid conflict and duplication in relation to the appointment of guardians and administrators should they be required.

Central registration, within the existing state-based guardianship systems, also connects people with an existing system of safeguards in the form of opportunities for tribunal review and oversight of Public Guardians and Trustees. While this will not provide all the safeguards needed, it helps to have people connected with an existing and substantial system.

There are great challenges with ensuring safeguards for people engaged in informal supportive relationships. One of the key concerns expressed about the provision of informal decision-making support is that it may expose vulnerable people with impaired decision-making capacity to manipulation, coercion or abuse.<sup>31</sup> Further to this, multiple appointments under a range of legislation could increase the risk that abuse, neglect and exploitation remains undiscovered.

The discussion in relation to safeguards opens up complex arguments about the 'dignity of risk' and the right of people with disabilities to take their own risks in decision-making, and highlights tensions between autonomy and paternalism. Many commentators suggest that further research is necessary to realise proper safeguards for people with disability in these arrangements.<sup>32</sup>

### **Representatives and NDIS Nominees**

In many ways, the role of a representative is similar to a guardian (noting the exceptions discussed above).

A number of potential issues arise as a result of this potential duplication in roles. First, it is unclear what would happen if an administrator or guardian was appointed for the same matter as the representative. Would the representative appointment override the guardian/administrator appointment or vice versa? It is also unclear who would make that determination so that the person, their family and carers and any third party agencies had certainty and clarity.

The Discussion Paper provides a number of proposals to address this possible conflict, all of which would require extensive cooperation and communication between state-based guardianship tribunals and public guardians, and individual Commonwealth agencies who may have appointed representative decision makers. This has the potential to be very burdensome for the agencies involved and confusing for people with disability, their families and carers as well as third party entities.

There is also currently no definite proposal for appointment, reviews, monitoring and safeguards. This is concerning given that the people for whom representatives will be appointed will require 'fully supported' decision-making. This should mean that any system of appointment should meet the standards required by Article 12 of the Convention, that is that:

*States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.<sup>33</sup>*

<sup>31</sup> Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, 'Supported Decision-Making: A Viable Alternative to Guardianship?' (2013) 117 Penn State Law Review 1111, 1114.

<sup>32</sup> Shih-Ning Then, 'Evolution and Innovation in Guardianship Laws: Assisted Decision-Making' (2013) 35 Sydney Law Review 133, 133; Terry Carney and Fleur Beaupert, 'Public and Private Bricolage – Challenges Balancing Law, Services and Civil Society in Advancing CPRD Supported Decision-Making' (2013) 36(1) University of New South Wales Law Journal 175; Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, 'Supported Decision-Making: A Viable Alternative to Guardianship?' (2013) 117 Penn State Law Review 1111.

<sup>33</sup> Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007 [2008] ATS 12 (entered into force 3 May 2008) Article 12.

The state-based guardianship legislation in each respective jurisdiction currently has extensive legislative frameworks for the appointment of guardians and administrators (including considerations of suitability); reviews of their appointments; and arrangements to vary and revoke the appointments when they are no longer required. In addition public guardians/ advocates have a protective and oversight role.

Similar issues to these identified for representative decision-makers (lack of oversight, safeguards and potential duplication and uncertainty when there is a conflict) also arise with regard to the role of the NDIS nominees under the NDIS Act.

Currently NDIS nominees are appointed by the CEO of the National Disability Insurance Agency (the 'NDIA'). While the CEO must have regard to whether the participant has a court-appointed decision-maker or a participant appointed decision-maker and any relevant views of a court-appointed decision-maker or a participant appointed decision-maker,<sup>34</sup> there continues to be a possibility that a nominee and a guardian could be appointed for the same matters.

There also seems to be evidence that in the launch sites for the NDIS, very few if any nominees have actually been appointed for participants. Where a person does not have the capacity to make their own decisions, it seems that these decisions have simply been made on their behalf by the NDIA. This was submitted in evidence in the recent case of KCG [2014]\_NSWCATGD 7 in the New South Wales Civil and Administrative Tribunal:

*In written submissions dated 1 April 2014, Special Counsel for the NDIA evidenced that, where a participant does not have the capacity to make the decisions required under the Act in relation to plan management and has no authorised representative, the NDIA would inquire as to the wishes of the participant, identify any informal supports available to prospective participants and then make a decision itself by taking into account all of the facts. The Tribunal understood these submissions to mean that in most circumstances where a participant was unable to self-manage, it was likely that plan management would be undertaken by the NDIA itself pursuant to s42(2)(c) of the NDIS Act.<sup>35</sup>*

This is very concerning and shows what can happen without a unified system with appropriate oversight and monitoring. The Office of the Public Advocate (Queensland) echoes the concerns expressed by the New South Wales Civil and Administrative Tribunal when it said:

*The Tribunal's view is that where important lifestyle and financial decisions are required to be made on behalf of a person who lacks the requisite decision making capacity (and cannot be supported to make decisions for themselves), such as Miss KCG, it is appropriate that an independent substitute decision maker such as guardian or financial manager (depending on the nature of the decision) is appointed to undertake that responsibility. The NDIS nominee scheme is a substitute decision making scheme designed for people with disability like Miss KCG...*

*The Tribunal considers that any substitute decision making regime must include appropriate safeguards to ensure that the rights of the person with the disability are not infringed and that the arrangements are regularly reviewed to ensure that, firstly, the appointed decision maker is acting in the person's best interests and, secondly, to vary or revoke arrangements where they are no longer needed. The Guardianship Act contains provisions to ensure that a guardian's authority is limited to the specific functions or areas of decision making where there is a current need for substitute decision making, orders are only in place for the shortest time possible and that they are subject to regular review by the Tribunal.<sup>36</sup>*

On this basis, there is a strong argument for the reconsideration of the nominee scheme, and lessons to be headed for the consideration of any new system of nominees/ representative decision-makers under other Commonwealth legislation.

<sup>34</sup> *National Disability Insurance Scheme (Nominee) Rules 2013* (Cth) rr 3.14(b)(iii), 3.14(b)(v)(C).

<sup>35</sup> KCG [2014] NSWCATGD 7 [60].

<sup>36</sup> KCG [2014] NSWCATGD 7 [67-68].

## Summary: a harmonised scheme driven by national decision-making principles

In principle, the Office supports the proposed Commonwealth decision-making principles that have the potential, along with appropriate legislative frameworks, training, education, advocacy and communication, to drive the kind of cultural change that is needed to achieve the goal of realising Article 12 of the Convention, as well as reform of state-based guardianship legislation.

Any decision-making model that the ALRC recommends, should ideally:

- avoid the creation of another system of substitute decision-making at a Commonwealth level;
- ensure harmony between the Commonwealth and state based guardianship laws/systems;
- provide for adequate safeguards for people with disability; and
- whether a best interests/rights-based, or combination of the two is applied, provide comprehensive guidance (including legislative guidance), training, education and communication about the transparent and principled application of such an approach.

A harmonised approach could include:

- the incorporation of the Commonwealth decision-making principles in Commonwealth legislation (including the NDIS Act and the *Disability Discrimination Act 1992*) and harmonisation with principles in state and territory guardianship legislation;
- the legislative recognition of the role of ‘supporters’ in relevant Commonwealth legislation, to enable supported decision-makers appointed by persons with disability to obtain and communicate information on behalf of people with relevant Commonwealth agencies; and
- the ability for persons who require or would like decision-making support to appoint supporters, who are then registered with state-based guardianship tribunals.

This harmonised approach should be accompanied by:

- a greater promotion of advance planning, including education and advice on the benefits of and how to make advance health directives and enduring documents; and
- enhanced and more coordinated access to the support and other services that people with disability need, including much greater case-management assistance.

A similar approach in other countries, such as Sweden, has reportedly been successful in reducing the country’s reliance on formal guardianship. Advocates for the Swedish system argue that in addition to formal guardianship it provides for a range of least restrictive alternatives, from support services to mentorships, which do not result in the loss of legal decision-making capacity for the adult,<sup>37</sup> and suggest that it is a good model for other countries that are faced with similar challenges. These challenges include how to support people with disability to navigate the array of social services they need without disempowering or disenfranchising them; and how to provide assistance with medical, financial and other issues that were once taken care of by institutional staff who exerted a *de facto* guardianship.<sup>38</sup>

Arguably the entitlement to social support, including personal assistance, also diminishes the need for guardianship. Ideally, the NDIS, if properly resourced and implemented, has the potential to help achieve the same result in Australia. What must be avoided however is a return to the situation where support agency staff make decisions on behalf of people with disability.

<sup>37</sup> Kristin Booth Glen, ‘Changing paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond’ (2012) 44(1) *Columbia Human Rights Law Review* 93, 142.

<sup>38</sup> Stanley S Herr, Self Determination, Autonomy and Alternatives for Guardianship <<http://ruralinstitute.umt.edu/transition/Handouts/Self-Determination.Herr.pdf>>. 142; Glen, above n 37, 141.

I would be pleased to further discuss the issues that I have noted in this submission should the Commission require additional information.

Yours sincerely



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