## Office of the Public Advocate (Qld)

### **Submission to Ernst & Young**

Independent Review of the Operation of the National Disability Insurance Scheme Act 2013 (Cth)

October 2015



The report is available online at <a href="https://www.publicadvocate.qld.gov.au">www.publicadvocate.qld.gov.au</a> or you may contact our Office for access to a hard copy.

Feedback on this report is welcomed. A hard copy may be requested from our Office.

The Queensland Government is committed to providing accessible services to Queenslanders from all culturally and linguistically diverse backgrounds. If you have difficulty in understanding the report, you can contact us on telephone (07) 3224 7424 or by emailing <a href="mailto:public.advocate@justice.qld.gov.au">public.advocate@justice.qld.gov.au</a> and we will arrange an interpreter to effectively communicate the report to you.



#### Disclaimer

Any views or opinions expressed in this document do not necessarily reflect the views of the Department of Justice and Attorney-General or the Queensland Government.

Every effort has been made to ensure this document is accurate, reliable and up to date at the time of publishing. The Office of the Public Advocate will not accept any responsibility for loss caused by reliance on this information and makes no representation or warranty regarding the quality or appropriateness of the data or information.

This work is copyright, however material from this publication may be copied and published without permission on the condition that the meaning of the material is not altered.

© The State of Queensland (Department of Justice and Attorney-General) 2015

### Introduction

### 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 (the adults) in all aspects of community life.

More specifically, the functions of the Public Advocate are:

- promoting and protecting the rights of the adults with impaired capacity for a matter;
- promoting the protection of the adults from neglect, exploitation or abuse;
- encouraging the development of programs to help the adults reach the 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 2015, the Office of the Public Advocate estimates that there are approximately 115,745 Queensland adults with impaired decision-making capacity (or 1 in 32 adults).<sup>2</sup> The primary factors that can impact decision-making capacity include (but are not limited to) intellectual disability, acquired brain injuries arising from catastrophic accidents, mental illness, ageing conditions such as dementia, and conditions associated with problematic alcohol and drug use.

It is important to note that not all people with these conditions will have impaired decision-making capacity, and that impaired decision-making capacity does not necessarily impact all areas of an adult's life, and may fluctuate in response to situational issues. It is likely, however, that many people with intellectual, cognitive or psychiatric disability may, at some point in their lives if not on a regular and ongoing basis, experience impaired decision-making capacity in respect of a matter.

 $<sup>^{\</sup>rm 1}$  Guardianship and Administration Act 2000 (Qld) s 209.

<sup>&</sup>lt;sup>2</sup> Office of the Public Advocate, 'The Potential Population for Systems Advocacy' (Fact Sheet, Office of the Public Advocate (Queensland), April 2015).

# National Disability Insurance Scheme Act 2013

### Interest of the Public Advocate (Qld)

# The National Disability Insurance Scheme and the Convention on the Rights of Persons with Disabilities

#### The Convention, rights and reasonable accommodation

This submission is focused on ensuring the legislative framework for the National Disability Insurance Scheme (the NDIS) comes as close as possible to realising the objectives of the United Nations *Convention on the Rights of Persons with Disabilities* (the Convention),<sup>3</sup> and as such ensuring Australia has a legislative framework and service system that incorporates a thoroughly contemporary and rights-based approach to people with disability.

The Convention has heralded a recent paradigm shift; that is, a new way of thinking about disability. Underpinned by what is known as the 'social model of disability', the Convention incorporates a contemporary approach to disability and emphasises the importance of:

- recognising that disability is an evolving concept and that disability results from the interaction between people with impairments and their surroundings as a result of attitudinal and environmental barriers;
- the right and capacity of people with disability to make valued contributions to their communities; and
- recognising that all categories of rights apply to people with disability, who should therefore be supported to exercise those rights.

An important overarching principle in the Convention is that of 'reasonable accommodation'. This refers to the support, modifications and adjustments that must be made so that people with disability can exercise their rights on the same basis as others. Importantly, discrimination is now defined by Article 5 of the Convention to also mean the failure to provide adequate accommodation. This broadens the concept of discrimination from the traditionally 'reactive' approach to providing a variety of remedies to discrimination in particular areas of life on the basis of disability, towards a positive obligation on state parties to ensure that people with disability have the information, assistance and support they need to exercise their rights.

Of particular relevance to the NDIS and this submission is Article 12 that imposes an obligation on state parties to recognise that people with disability enjoy legal capacity on an equal basis with others. It places a specific and positive obligation on state parties to "take appropriate"

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

measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."<sup>4</sup>

Read with Article 5, an overarching principle of equality and non-discrimination, there is an obligation on state parties to ensure support is provided to people with disability to enable them to exercise their legal capacity, so as to avoid discrimination.

## The National Disability Insurance Scheme – realising the objectives of the Convention

Prefaced on the principles of choice and control as opposed to a paternalistic welfare model that has predominated the delivery of disability services, the National Disability Insurance Scheme (NDIS) represents a significant step toward addressing the deficiencies of the current disability service systems that exist across Australia, and to advancing cultural change and genuine social inclusion.

Yet, realising these objectives and ensuring consistency with the Convention will require significant changes to the way disability services have been delivered, as well as modernisation of our legislative frameworks. This includes not only the NDIS legislative framework but other legislation impacting on the operation of the NDIS including discrimination legislation, and in particular the legislation underpinning the state and territory guardianship regimes.

In light of the paradigm shift heralded by the Convention and the move away from the idea of people with disability as objects of social protection to being that of rights bearers, relevant legislative frameworks (including the *National Disability Insurance Scheme Act 2013* (Cth) (the NDIS Act)) should be updated to take a positive and proactive approach to the rights of persons with disability. The principles, objectives and substantive parts of the legislation should ensure there is a positive onus to provide 'reasonable accommodation' or support, assistance and information in different areas of public life to ensure that people with disability can exercise their rights.

# A system designed for people who may need assistance with exercising choice and control

Data from the quarterly NDIS report for March 2015 confirms that 89% of NDIS participants may have some form of cognitive impairment.<sup>5</sup>

The NDIS legislative and policy frameworks must ensure that the needs of people with disability who may experience difficulties in making decisions are accommodated. Whilst continuing to uphold the common law presumption of capacity, legislation, policy and systems must be designed so that people who experience difficulties in making decisions due to an

\_

<sup>&</sup>lt;sup>4</sup> Ibid art 12(3).

<sup>&</sup>lt;sup>5</sup> National Disability Insurance Agency, *Quarterly Report to COAG Disability Reform Council 31 March 2015* (2015) National Disability Insurance Scheme, 52 <a href="https://www.ndis.gov.au/sites/default/files/files/Q3Report2015.pdf">https://www.ndis.gov.au/sites/default/files/files/Q3Report2015.pdf</a>. Data excludes NDIS participants from South Australia (as they are under 18 years of age) and includes NDIS participants with a primary disability of autism and related disorders, cerebral palsy, developmental delay, down syndrome, global developmental delay, intellectual disability, schizophrenia, 'other intellectual/learning', 'other neurological' and 'other psychiatric'. Deafness/hearing loss, multiple sclerosis, 'other physical' and 'other sensory/speech' were not included in the group of primary disabilities which may lead to cognitive impairment.

intellectual, neurological, psychological or other cognitive impairment are provided with the support and assistance they need to navigate the system and exercise choice and control.

Specifically the NDIS legislative and policy framework must ensure that there are no barriers in the way to becoming a participant and developing, managing and reviewing a plan because a person experiences difficulties in exercising their decision-making capacity. Whilst the NDIS Act provides a requirement for the National Disability Insurance Agency (the Agency) to provide support and assistance to prospective participants and to eligible participants,<sup>6</sup> this requirement must be strengthened and expanded upon to truly realise Australia's obligations under the Convention.

**Recommendation:** Whilst continuing to uphold the common law presumption of capacity the NDIS legislative and policy framework must ensure that the needs of people with disability who may experience difficulties in making decisions are accommodated. Legislation, policy and systems must be designed so that people who experience difficulties in making decisions due to an intellectual, neurological, psychological or other cognitive impairment are provided with the support and assistance they need to navigate the system and exercise choice and control.

This submission focuses on two issues:

- the objects and principles of the NDIS Act; and
- implementing the obligation of state parties to provide decision-making support.

# Objects and Principles of the *National Disability Insurance Scheme Act*

While overall the objects and principles of the NDIS Act generally reflect the spirit of the Convention, there are two issues that will be raised:

- the need to recognise the requirement of reasonable accommodation and the obligation to provide support in relation to decision-making, in particular to realise Article 12 of the Convention; and
- consistency with the Australian Law Reform Commission's recommended National Decision-Making Principles.<sup>7</sup>

As will be argued below, to give full effect to the Convention and the obligation to accommodate and provide necessary support in terms of decision-making (as required by Article 12), such obligations must be embedded in relevant legislation, including the NDIS legislative framework.

<sup>&</sup>lt;sup>6</sup> National Disability Insurance Scheme Act 2013 (Cth) s 6.

<sup>&</sup>lt;sup>7</sup> Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* (Report 124).

<sup>&</sup>lt;sup>8</sup> Michael Bach and Lana Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity* (October 2010, Prepared for the Law Commission of Ontario) 109.

# Reasonable accommodation, support and Article 12 of the Convention (decision-making)

#### Reasonable accommodation in decision-making

The obligation to provide *reasonable accommodations* implicates not only state parties to the Convention, but also third parties engaged in some way in the decision-making process.<sup>9</sup> Accommodations to enable participation in decision-making may come from a variety of avenues and mechanisms (not just that facilitated by the NDIS) such as:

- providing information in a format that can be easily understood by the person;
- allowing for informal assistance from family and friends;
- arranging for an interpreter (for a person who is deaf for example) or another person (for example a speech therapist for a person with verbal communication difficulties) to assist with communication; and
- recognising and accommodating supported decision-making representatives (both formal and informal).

The types of accommodations that may need to be made will depend entirely on the person, and in some situations may involve ensuring a support person is provided to help the person make the decision, and in others it may mean providing for extra time for a person to digest the information being provided.<sup>10</sup>

As Bach and Kerzner have articulated:

"The concept of accommodation describes a legal duty to take positive action to accommodate the unique needs of people with disabilities. More specifically, 'Accommodation' refers to what is required in the circumstances to avoid discrimination. Its goal is to avoid exclusion by ensuring the fullest possible participation in society."<sup>11</sup>

As such the NDIS legislative framework, including the principles, should explicitly reflect the obligation on all parties interacting with people with disability as part of the scheme to make *necessary accommodations* to assist people with disability to participate in decision-making, which will in turn, facilitate their exercise of choice and control under the NDIS.

Such an approach is modelled in a number of international jurisdictions' statutes, including for example the *Equality Act 2010 (UK)* that imposes a duty to make reasonable adjustments, to ensure that people with disability are not put at a disadvantage in comparison to people who do not have a disability, which includes an obligation to take such steps as is reasonable. <sup>12</sup>

<sup>10</sup> Ibid 105.

<sup>&</sup>lt;sup>9</sup> Ibid.

<sup>&</sup>lt;sup>11</sup> Ibid 104.

<sup>&</sup>lt;sup>12</sup> Equality Act 2010 (UK) s 20.

#### Support for decision-making

The specific obligation on state parties to the Convention is to provide the necessary *supports* to people with disability to exercise their legal capacity.

The concept of support to exercise choice and control is acknowledged in the NDIS Act, as evidenced through provisions such as: "People with disability should be supported to receive reasonable and necessary supports, including early intervention supports" and that "Reasonable and necessary supports for people with disability should:

- (a) support people with disability to pursue their goals and maximise their independence; and
- (b) support people with disability to live independently and to be included in the community as fully participating citizens; and
- (c) develop and support the capacity of people with disability to undertake activities that enable them to participate in the mainstream community and in employment."<sup>14</sup>

What is missing is not only a specific and positive focus on the obligation of state parties and others engaged in a decision-making process with people with disability to make necessary accommodations (as discussed above), but also the specific obligation on state parties to provide support to exercise actual decision-making capacity consistent with Article 12 of the Convention. While it may be implied in a number of the principles, the positive obligation inherent in the Convention (Articles 5 and 12) is not explicit.

Decision-making support is crucial to people with disability (particularly people with impairments which may impact on their decision-making ability) to realise the goals and aspirations of the NDIS as articulated in the NDIS principles in particular to—

"...enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports." <sup>15</sup>

The actual practical provision of support is discussed in the next section. The principles, however should recognise a person's specific right to support in decision-making, a prerequisite to exercising choice and control for many people with impairments that affect their decision-making abilities.

**Recommendation:** The NDIS legislative framework, including the principles (sections 4 and 5) should reflect the obligation on all parties interacting with people with disability as part of the scheme to make necessary *accommodations* to assist people with disability to participate in decision-making, which will in turn, facilitate their exercise of choice and control under the NDIS.

**Recommendation**: The NDIS legislative framework, including the principles should recognise a person's specific right to *support in decision-making*, a prerequisite to exercising choice and control for many people with impairments that affect their decision-making abilities.

<sup>&</sup>lt;sup>13</sup> National Disability Insurance Act 2013 (Cth) s 4(5).

<sup>&</sup>lt;sup>14</sup> Ibid s 4(11).

<sup>15</sup> Ibid s 3(1)(e).

#### **ALRC and the National Decision-Making Principles**

The Discussion Paper notes the Australian Law Reform Commission's (ALRC) Final Report, *Equality, Capacity and Disability in Commonwealth Laws*<sup>16</sup> and the recommendation to amend the objects and principles of the NDIS Act to ensure consistency with the national decision-making principles.

In principle, the Office of the Public Advocate 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.

#### Proposed national decision-making principles - ALRC

- 1. All adults have an equal right to make decisions that affect their lives and to have those decisions respected.
- 2. Persons who may require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.
- 3. The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.
- 4. Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.<sup>17</sup>

**Recommendation**: The objects and principles of the NDIS Act should be reviewed to ensure consistency with the proposed ALRC national decision-making principles.

### **Decision-making support**

# Provision of actual support to exercise decision-making capacity

Section 6 of the NDIS Act states that: "To support people with disability to exercise choice and control in the pursuit of their goals, the Agency may provide support and assistance (including financial assistance) to prospective participants and participants in relation to doing things or meeting obligations under, or for the purposes of, this Act."

Where additional supports are required to enable the exercise of a person's legal capacity to make decisions beyond which a third party can provide through various accommodations (such as information provided in a format which the person can understand) in accordance with Article 12 of the Convention, state parties also have an obligation to provide support to a

<sup>&</sup>lt;sup>16</sup> Australian Law Reform Commission, Equality, Capacity and Disability in Commonwealth Laws (Report 124, August 2014).

<sup>&</sup>lt;sup>17</sup> Ibid Recommendation 3-1.

person to enable them to exercise their decision-making capacity, and as such exercise choice and control.<sup>18</sup>

The facilitation of this support, of course, will depend on more than just the NDIS and will have implications for the states' guardianship regimes (in terms of legal authority and recognition) and people's informal networks including family, friends and community. The NDIS, however does play a crucial role.

Anecdotal feedback received from trial sites is that there has been a heavy reliance on guardians and guardianship agencies by people with impaired decision-making capacity, to access the NDIS, develop a plan and activate or operationalise that plan. Yet guardianship is one of the most restrictive ways in which this assistance can occur. The formal appointment of a guardian results in the loss of legal capacity by the person. It should be an absolute last resort.

Experiences in other countries, such as Sweden, have shown that with inclusive systems of entitlement to support for people with disability, including the provision of personal assistance, the need for guardianship and other forms of substitute decision-making, which deny people their legal rights to exercise capacity, can be reduced. For example, in Sweden, the law<sup>19</sup> makes a personal assistant a mandated support service for people with disability covered by the scope of the legislation.<sup>20</sup>

In Australia, there is a similar potential for the NDIS to also play a central role in facilitating and enabling a less restrictive alternative than the guardianship system to navigate the array of social, medical, financial and other services that people with disability might need.

To realise the potential of a less restrictive alternative, the NDIS legislation and policy framework must not only ensure that there are not barriers in the way to becoming a participant and developing, managing and reviewing a plan for people with intellectual, neurological, psychological or other cognitive impairments who have difficult with decision-making, but actively also facilitate the provision of the support necessary to join and participate in the scheme.

Support in decision-making may take a variety of forms and include:

- Informal support provided by family and friends;
- Formal support provided by an appointed 'supporter' (either under legislation or an agreement);
- Formal support provided by a guardian or attorney (although the appointment of a guardian/ attorney does mean the person has lost their formal decision-making capacity and is not what is normally regarded as 'supported decision-making').

Whilst the NDIS Act provides a requirement for the National Disability Insurance Agency (the Agency) to provide support and assistance to prospective participants and to eligible

<sup>&</sup>lt;sup>18</sup> Convention on the Rights of Persons with Disabilities, art 12(3); Michael Bach and Lana Kerzner, above n8, 114.

<sup>&</sup>lt;sup>19</sup> Lag om stod och service till vissa funktionshindrade (which came into effect in 1994 and gives people with disability the right to ten different kinds of support and services).

 $<sup>^{20}</sup>$  Stanley S Herr, Self Determination, Autonomy and Alternatives for Guardianship

 $<sup>&</sup>lt;\!\!\underline{\text{http://ruralinstitute.umt.edu/transition/Handouts/Self-Determination.Herr.pdf}}\!\!>\!.$ 

participants,<sup>21</sup> this requirement must be strengthened to include a legislative mandate to recognise and facilitate support to decision-making assistance if it is needed.

The implementation of this concept of support to exercise decision-making will require detailed consideration of the model in practice and funding of such supporters. As suggested by the ALRC, where a person does not have access to appropriate support, support could conceivably by funded through the NDIS participants' packages of support,<sup>22</sup> or they could be funded separately by the NDIA or other government agencies such as the National Disability Advocacy Program (NDAP) managed by the Department of Social Services that funds advocates at NDIS trial sites.<sup>23</sup>

**Recommendation:** The NDIS Act should be amended to recognise the obligation to ensure support is available to a person with disability where it is required for them to exercise their capacity to make decisions.

### Nominees under the National Disability Insurance Scheme Act

The nominee scheme under the NDIS recognises that in some instances participants may require a person to act on, or make decisions on their behalf. This may be applicable for many people with intellectual, neurological, psychological or other cognitive impairments.

While the NDIS Act allows for a plan nominee to be appointed to act on behalf of the participant in the preparation and review of the participant's plan and the management of funding and supports under the plan,<sup>24</sup> there is some confusion about how this scheme will work with the state based guardianship systems. Further, the nominee scheme is essentially a substitute-decision making regime, which is not consistent with the least restrictive approach to people with disability who may experience difficulties in making decisions and as such not consistent with Article 12 of the Convention, nor the recommended approach by the ALRC.

#### Nominees and state guardianship regimes

The appointment of a nominee, in particular a plan nominee, currently has the effect, similarly to the appointment of a guardian, of removing the person's legal rights to make decisions under the scheme.

Given this position of nominees as de facto substitute decision-makers there is much potential for conflict and duplication where a guardian and/or administrator has also been appointed by a respective state guardianship tribunal or board.

As such it is important that the interaction between the NDIS Act, the NDIS Rules and the state-based guardianship and administration legislation is further clarified. While there is currently a 'presumption' that an existing guardian would also be appointed as a nominee for a participant, this is not sufficient.

<sup>&</sup>lt;sup>21</sup> National Disability Insurance Scheme Act 2013 (Cth) s 6.

<sup>&</sup>lt;sup>22</sup> Australian Law Reform Commission, above n16, 139

<sup>&</sup>lt;sup>23</sup> Ibid 140

<sup>&</sup>lt;sup>24</sup> National Disability Insurance Act 2013 (Cth) s 78(2).

Currently NDIS nominees are appointed by the CEO of the Agency. 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>25</sup> there continues to be a possibility that a nominee and a guardian could be appointed for the same matters.

To address this possible conflict, it 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.

Under Queensland's *Guardianship and Administration Act 2000*, the Queensland Civil and Administration Tribunal determines whether a person has impaired decision-making capacity relating to specific decisions, based on medical and other evidence following a hearing. The Tribunal also appoints a person to act as a guardian for a person with impaired decision-making capacity to ensure the interests of the adult with impaired decision-making capacity are protected and their needs are met.

It is not appropriate that the NDIS Agency should have the discretion to override such an appointment, and appoint a nominee to perform a duty that a guardian or administrator may have been appointed to perform.

Further, the states regimes for the appointment of guardians and administrators not only come with appropriate procedures and due process associated with the legislative framework and procedures of the respective tribunals, but they also offer existing safeguards for the actions of substitute decision-makers including guardians, administrators and attorneys. Such safeguards include provision for tribunal review of appointments and the oversight and protections provided by respective public guardians/ advocates.

The current nominee scheme has little in the way of reviews, monitoring and safeguards. Any system of appointment should meet the standards required by Article 12 of the Convention, that is:

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>26</sup>

The NDIS nominee scheme does not meet this threshold.

Some NDIS participants may have also have an enduring power of attorney, a person that they have nominated to make these types of decisions for them. Where a participant has an

<sup>&</sup>lt;sup>25</sup> National Disability Insurance Scheme (Nominee) Rules 2013 (Cth) rr 3.14(b)(iii), 3.14(b)(v)(C).

<sup>&</sup>lt;sup>26</sup> Convention on the Rights of Persons with Disabilities, Art 12.

existing guardian or attorney with the relevant decision-making authority, the Agency must appoint the identified attorney or guardian as the participant's nominee.

In practice, it seems 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>27</sup>

This is very concerning and shows what can happen without a unified system with appropriate oversight and monitoring. Such concerns were 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>28</sup>

On this basis, there is a strong argument for the reconsideration of the nominee scheme, and lessons to be heeded for the consideration of any new system of nominees/representative decision-makers under other Commonwealth legislation. Any reforms of the system will require an extensive cross-jurisdictional analysis and cooperation between all jurisdictions in order to provide an effective and efficient system that assists NDIS participants and does not hinder them through complicated and duplicated bureaucratic procedures.

<sup>&</sup>lt;sup>27</sup> KCG [2014] NSWCATGD 7 [60].

<sup>&</sup>lt;sup>28</sup> Ibid [67-68].

#### Supported decision making

The current regime of nominees under the NDIS Act only has provisions for a 'correspondence nominee' and 'plan nominee' and is modelled largely on the existing nominee scheme under other Commonwealth legislation such as the *Social Security Act 1991* (Cwth).

As discussed above this is not consistent with Article 12 of the Convention or the least restrictive approach. The provision of advice, personal assistance and other alternatives should be further explored in legislation, policy and procedures prior to the appointment of nominees.

The Commonwealth Decision-Making Model proposed by the ALRC provides a much greater emphasis on the supported decision-making model and is more consistent with the Convention.

The role of **supporters** as outlined by the ALRC 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>29</sup>

The role of the **representative** as outlined by the ALRC 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.<sup>30</sup>

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. In principle, the Office of the Public Advocate broadly supported the proposed model 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.

However, support for this model is reserved through the position that decision-making model should ideally avoid the creation of another system of substitute decision-making at a Commonwealth level and importantly ensure harmony between the Commonwealth and state based guardianship laws/systems. As such, for example, it is envisaged that 'representatives' could refer to the state tribunal appointed guardians. Adequate safeguards must also be ensured for people with disability.

12

<sup>&</sup>lt;sup>29</sup> Australian Law Reform Commission, above n16, 103.

<sup>&</sup>lt;sup>30</sup> Ihid 111.

Should the NDIS Act implement the Commonwealth Decision-Making Model, there are still a number of considerations that need to be had to ensure the effectiveness of this model and its interaction with existing laws. Yet, it would seem this is necessary work given the significant paradigm shift heralded by the NDIS to Australia's legislative, policy and service system approach to disability.

**Recommendation:** The nominee scheme should be reconsidered. A review of the scheme should take place in light of the ALRC recommendations for a Commonwealth Decision-Making model and the need for harmonisation with states and territories guardianship regimes.

### Conclusion

To fully realise the principles underpinning the NDIS and to bring Australia into line with the Convention and contemporary approaches to disability requires a harmonised system (that synchronises legislation, policy and support systems) to truly enable people with disability to make decisions that facilitates their ability to exercise choice and control over their lives.

A range of least restrictive alternatives, from support services and advocates to formally appointed supporters, which do not result in the loss of legal decision-making capacity, are required to realise this vision. This requires not only a 'paradigm' shift in the way disability support services are delivered, but also principles and positive duties embedded in relevant legislation.

Ideally the NDIS, if properly resourced and implemented, has the potential to help achieve this in Australia.

It is hoped that this independent review into the NDIS Act will become the catalyst in the implementation of least restrictive supportive arrangements that are consistent with the Convention and contemporary approaches to disability in not only this legislation, but for others throughout the country.

Thank-you for the opportunity to make this submission to the independent review of the NDIS Act. I would be pleased to further discuss the issues that I have noted in this submission should the Commission require additional information.

Yours sincerely

Kim Chandler

**Acting Public Advocate** 

M. Chandler

Office of the Public Advocate (Queensland)

#### Office of the Public Advocate

Website <a href="www.publicadvocate.qld.gov.au">www.publicadvocate.qld.gov.au</a>
Email <a href="public.advocate@justice.qld.gov.au">public.advocate@justice.qld.gov.au</a>

Write to GPO Box 149, BRISBANE QLD 4001

Telephone (07) 3224 7424