



Office of the Public Advocate

Safeguarding the rights and interests of people with disability

## **Submission on the development of an NDIS Supported Decision Making Policy**

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**Office of the Public Advocate**  
Level1, 204 Lygon Street, Carlton,  
Victoria, 3053  
Phone: 1300 309 337  
NRS: 133 677  
[www.publicadvocate.vic.gov.au](http://www.publicadvocate.vic.gov.au)

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## Abbreviations

ARF	Access Request Form
GAA	Guardianship and Administration Act 2019 (Victoria)
OPA	Office of the Public Advocate
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
VCAT	Victorian Civil and Administrative Tribunal

# Recommendations

## Recommendation 1

The National Disability Insurance Agency should provide decision support for participants who require it to promote the human rights of people with disability to exercise choice and control.

## Recommendation 2

The National Disability Insurance Agency should fund:

- Decision support for day-to-day lifestyle, personal and financial decisions
- Decision support in advance of significant life transitions
- Decision support for NDIS-related planning.

## Recommendation 3

The National Disability Insurance Agency should provide capacity building and training opportunities, supported decision-making tools and resources for non-professional decision-supporters.

## Recommendation 4

The National Disability Insurance Agency should continue to fund innovative supported decision-making initiatives.

## Recommendation 5

The National Disability Insurance Agency should develop guidelines that define the scope and responsibilities of the Decision-Supporter role, to include an advocacy element.

## Recommendation 6

The National Disability Insurance Agency's administrative processes should be sufficiently flexible to ensure that participants can implement decisions made with support.

# 1. Office of the Public Advocate

The Office of the Public Advocate (OPA) is a Victorian statutory office, independent of government and government services, that works to safeguard the rights and interests of people with disability. The Public Advocate is appointed by the Governor in Council and is answerable to the Victorian State Parliament.

The Public Advocate has seven functions under the *Guardianship and Administration Act 2019* (Vic) (GAA), all of which relate to promoting the independence and human rights of people with disability and protecting people with disability from abuse, neglect, and exploitation. To this end, OPA provides a range of critical services for people with cognitive impairment or mental illness, including guardianship, advocacy, and investigation services. In 2019-20, OPA was involved in 1792 guardianship matters (950 which were new), 430 investigations, and 284 cases requiring advocacy.<sup>2</sup> In recent years, the profile of its clients has begun to change. As in previous years, the complexity of cases remains a key feature of guardianship matters, each of which has multiple dimensions ranging from complex disability presentations and service provision arrangements to complex family dynamics. A key contributor to this increasing complexity is the introduction of the National Disability Insurance Scheme (NDIS), and the interface with the justice system, in addition to the lack of appropriate and accessible housing for people with complex and challenging support needs.

A key function of the Public Advocate is to promote and facilitate public awareness and understanding about the *Guardianship and Administration Act 2019* and any other legislation affecting persons with disability or persons who may not have decision-making capacity. To do so, OPA supports a full-service communications function with 120 publications in print or PDF, a website attracting over 200,000 visitors a year and strong media relations. It also operates an Advice Service which provided 12,624 instances of advice last financial year. OPA also coordinates a community education program for professional and community audiences across Victoria to engage on a range of topics such as the role of OPA, guardianship and administration, and enduring powers of attorney.

OPA is supported by more than 700 volunteers across three volunteer programs: the Community Visitors Program, the Independent Third Person Program (ITP Program) and the Corrections Independent Support Officer (CISO) Program. The ITP Program is an on-call, state-wide service operating in all police stations in Victoria. ITPs assist persons with cognitive impairment when making formal statements to Victoria Police. In 2019-20, ITPs attended a total of 3718 interviews. CISOs are experienced ITPs who support prisoners who have an intellectual disability at Governor's disciplinary hearings at Victorian prisons and/or remand centres. Between July 2017 to March 2020, CISOs attended 254 hearings at seven Victorian prisons.

Community Visitors are independent volunteers empowered by law to visit Victorian accommodation facilities for people with disability or mental illness. They monitor and report on the adequacy of services provided in the interests of residents and patients. They ensure that the human rights of residents or patients are being upheld and that they are not subject to abuse, neglect, or exploitation. In their annual report, Community Visitors relate their observations on the quality and safety of the services they visit and make recommendations to the Victorian State Government. More than 400 Community Visitors visit across three streams: disability services, supported residential services and mental health services. In 2018-19, Community Visitors made 4142 statutory visits, including to sites of criminal and civil detention.

## 2. Introduction

The Office of the Public Advocate (OPA) supports the introduction of a National Disability Insurance Scheme (NDIS) Supported Decision-Making Policy to further the human rights of people with disability, particularly those with significant cognitive impairment.

This submission is based on the experience of OPA staff and volunteers and the people they work with and focusses on the interface of supported decision-making with substitute decision-making. This includes consideration of:

- the types of decisions that should be included in the policy
- the funding of innovative programs to establish and train a cohort of independent Decision-Supporters, where NDIS participants do not have anyone in their lives who can fulfil this role
- how supported decision-making can address an over-reliance on substitute decision-makers for NDIS-related decisions.

### 2.1 Human rights approach

This submission applies a human rights approach that:

- holds that all people with disability have the right to enjoy equality of opportunity and to effectively participate in, and be fully included in, society
- recognises that the vast majority of challenges experienced by people with disability are a result of disabling systems and environments, rather than being due to an inherent 'lack' in the individual
- considers impairment as an expected dimension of human diversity
- seeks for people with disability to be supported and resourced to have the capabilities to lead a dignifying and flourishing life.

In writing this submission, OPA takes into account the following legislative instruments that promote and protect the human rights of people with mental illness and/or disability:

- the United Nations Convention on the Rights of Persons with Disabilities
- the Optional Protocol to the Convention Against Torture
- *Disability Discrimination Act 1992* (Cth)
- *National Disability Insurance Scheme Act 2013* (Cth)
- *Guardianship and Administration Act 2019* (Vic)
- *Charter of Human Rights and Responsibilities Act 2006* (Vic)
- *Mental Health Act 2014* (Vic).

## 3 Entitlement to decision-making support

People with cognitive disability who require support to make decisions are entitled under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to it<sup>1</sup>. The fundamental values underpinning the NDIS, those of choice and control for people with disability over their lives, are enlivened only when genuine decision-making is facilitated as part of the fabric of daily life.

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<sup>1</sup> UN General Assembly, *Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106*

Decision support must also be in place when people with disabilities are making significant decisions, here, most notably, as part of NDIS planning.

### **Recommendation 1**

**The National Disability Insurance Agency should provide decision-support for participants who require it to promote the human rights of people with disability to exercise choice and control.**

## **4 Development of decision-making skills**

### **4.1 Building decision-making capacity**

NDIS funding must enable the day-to-day lifestyle, personal and financial decisions of a person who requires the skilled support of a decision-supporter. This requires the provision of decision-making support, over a period of time, in order to build the decision-making capacity of participants.

Evidence of the importance of decision-making capacity building emerged during the 2016 OPA and VALID pilot supported decision-making project (the OVAL project<sup>2</sup>). Under the trial, volunteers were trained and supported to work with NDIS participants. Participants were selected on the basis of both their interest in the project and their need for an independent Decision-Supporter (in circumstances where there was no other person in their life to undertake the role).

A key learning from this piece of work was that many of the participants had few prior opportunities to make decisions, with or without support, in their day-to-day lives. This meant that they were overwhelmed when faced with the level of decision-making required in relation to their NDIS Plan. Opportunities for the development of decision-making skills, over time and as part of day-to-day life, were observed to be a necessary element of decision-making capacity building.

Developing skills to make daily decisions is, for people who have not had many opportunities to make decisions throughout their lives, essential to increase their capacity to make the more complex decisions required as part of their NDIS planning. This can be achieved by ensuring that NDIS participants are able to purchase such supports through their NDIS plan.

By way of illustration, we look to a familiar and growing cohort of people for whom the Public Advocate is guardian: young adults who had been in long-term foster care prior to reaching 18 years of age. Having had few prior opportunities to develop decision-making skills, they are assessed by VCAT as being unable to make relevant decisions by reason of their disability, and requiring a substitute decision-maker to develop their NDIS plans. However, OPA has observed that some of these young people, given enough time, opportunity, and the support of a skilled decision-supporter, do develop capacity to make their own decisions.

A particular focus for NDIS funding might be the period *in advance of* this life stage transition to adulthood. The availability of funding over time for these young people to develop decision-making skills with support, would mean they would be able to make NDIS-related decisions for themselves with support, and the more restrictive option of substitute decision-making may be unnecessary.

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<sup>2</sup> Office of the Public Advocate (2017). Volunteer Programs of Support for Decision-Making: Lessons and recommendations from the OVAL Project.

## **Recommendation 2**

**The National Disability Insurance Agency should fund:**

- **Decision support for day-to-day lifestyle, personal and financial decisions**
- **Decision support in advance of significant life transitions**
- **Decision support for NDIS-related planning.**

## **5. Decision-Supporters**

### **5.1 Building the capacity of Decision-Supporters**

OPA acknowledges that, for people with cognitive impairment who require support with decision-making, those best placed to offer support are often those who know the person well and can determine and interpret the person's will and preference.

High quality and skilled decision support is a requirement for the enactment of the human rights of people with disability who require support to exercise choice and control in their lives. Decision-Supporters should have access to high quality resources, tools, as well as capacity-building training to enable best practice. Accessible, NDIS-related, decision-making information must be available to all decision-supporters.

## **Recommendation 3**

**The National Disability Insurance Agency should provide capacity building and training opportunities, supported decision-making tools and resources for non-professional decision-supporters.**

### **5.2 Decision support for people with no close supports**

Some NDIS participants do not have friends, family or other impartial actors to fulfil the decision-supporter role. For this cohort, the NDIA must fund decision support programs to enable choice and control to allow people with disabilities to exercise their rights.

There have been a number of supported decision-making pilot programs. For example, the OVAL Project, previously mentioned, was a pilot which invited volunteers to take on the role of decision-supporter. The project involved matching volunteers trained in the practice of support for decisions making with NDIS participants who wanted and needed this type of support.

The outcomes of the project were independently evaluated. Both the NDIS participants and volunteer supporters felt that their relationship was very positive. NDIS participants appreciated the support from someone from outside the service sector who, they reported, would not tell them what to do. The decision-making support provided by the volunteers led to significant changes in the lives of those with disability, including: changes to support plans; service providers; life stages (for example, getting engaged); finding employment; and commencing education.

The volunteers who gave their time and energy to the project demonstrated that the general community is a rich resource from which to draw decision-supporters. The recommendations that emerged from the project emphasis that capacity building, training and ongoing support for volunteers is essential for successful outcomes. A successful second phase of this project, Choice Mentors, was subsequently developed and delivered by VALID.

To ensure sustainable and quality practice, the NDIA should fund a small number of innovative supported decision-making initiatives throughout Australia, through which people with impaired decision-making ability are supported to make NDIS-related decisions. Project funding should be determined on a competitive basis and should be sufficient to enable these initiatives to be evaluated robustly, with a view to the most successful programs being implemented throughout Australia.

#### **Recommendation 4**

**The National Disability Insurance Agency should continue to fund innovative supported decision-making initiatives.**

### **5.3 Decision-Supporters as advocates**

The role of Decision-Supporter includes many elements, variously described by practice leaders in the field, but usually includes elements such as the following, adapted from the La Trobe Framework for Decision Support: getting to know the person, identifying the decision/s, exploring options and opportunities, understanding the person's will and preferences, reaching the decision and associated decisions, and implementing the decision.<sup>3</sup>

In relation to NDIS-related decisions, the role of the Decision-Supporter in implementing decisions may be complex. Primarily, the Decision-Supporter must ensure that NDIS Support Coordinators are fully aware of, and engaged with the decisions made as part of the supported decision-making process. They must also ensure that service providers deliver services in line with decisions made.

The role of Decision-Supporter must, therefore, include a formal and recognised advocacy element in order to ensure the effective implementation of participants' decision-making. For example, the Decision-Supporter may support the participant to make complaints, or make complaints on their behalf, seeking outcomes in line with decisions made. Complaints may concern instances of Support Coordinators or service providers not fulfilling their obligations to implement the decisions in line with the participants' will and preferences.

#### **Recommendation 5**

**The National Disability Insurance Agency should develop guidelines that define the scope and responsibilities of the Decision-Supporter role, to include an advocacy element.**

## **6. Addressing an over-reliance on substitute decision-makers**

### **6.1 Least restrictive option**

An NDIS Supported Decision-Making Policy must consider the needs of people who do not have capacity to consent to supported decision-making or to meet administrative requirements under the scheme in circumstances where substitute decision-making is not required. OPA observes that, for this cohort, there can be an over-reliance on substitute decision-makers, without due regard to the obligation of engaging least-restrictive options.

Whether in relation to plan nominees, advocate guardians, administrators, or other substitute decision-makers, substitute decision-making in the context of NDIS-related decisions should be restricted to situations of absolute necessity, and supported decision-making should be promoted and utilised, wherever possible.

### **6.2 Supported decision-making to meet NDIS administrative requirements**

An over-reliance on substitute decision-makers is particularly evident where support is needed for NDIS participants to complete administrative requirements of the NDIS access and planning process. OPA is concerned that, in an increasing number of cases, the NDIA is requesting

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<sup>3</sup> Bigby, C., Douglas, J., & Vassallo, S. (2019). The La Trobe Support for Decision Making Practice Framework. An online learning resource.

guardianship appointments for the sole purpose of enabling participants to complete the administrative requirements to enter the scheme and complete planning.

In one case, the Public Advocate was appointed as guardian for a person who had capacity to request access to the NDIS but could not physically sign the Access Request Form (ARF) due to the nature of her disability. She could, when provided with adequate support, verbally communicate her wishes and preferences, including her desire to enter the scheme. The potential participant's delegated guardian assisted with the completion of the ARF but the NDIA would not allow verbal consent from the prospective participant to the ARF and, instead, required the delegated guardian to sign. This is as an instrumental use of guardianship for administrative efficiency and is misaligned with the legislative intent of guardianship. Guardianship should remain, importantly, a measure of last resort, as it is prescribed in legislation.

In Victoria, the *Guardianship and Administration Act 2019 (Vic) (GAA)* prescribes that, when determining whether or not a person is in need of a guardian, the Victorian Civil and Administrative Tribunal (VCAT) must consider, among other considerations, "whether the needs of the person in respect of whom the application is made could be met by other means less restrictive of the person's freedom of decision and action."<sup>4</sup> Guardianship legislation in other jurisdictions replicates this provision.

In Victoria again, the GAA legislates the presumption that a person has decision-making capacity if the person can make decisions with support. In the case presented above, the potential participant had capacity to make and communicate her decision when provided with an alternative consent method. Requests for guardianship or requests made of guardians by the NDIA in these circumstances deny participants their right to have control of decisions that affect their lives where, with support, they have capacity to do so.

Rather, the Decision-Supporter's role should include the documentation of decisions made by the participant with support, where that documentation is necessary to fulfil NDIS administrative requirements. Where it is not possible for a NDIS provider's service agreement to be signed as the participant does not have legal capacity to do so, for example, the Decision-Supporter could facilitate the preparation of documentation which records the decisions made. In relation to an agreement to provide services, the Decision-Supporter could support the participant to liaise with an NDIS provider to produce a statement of support identifying the supports that the provider will provide to the participant (a statement of support), rather than the participant entering a service agreement. While the NDIA recommends that providers and participants enter a written service agreement, it is not a legislative or policy requirement to do so in order for a service provider to provide NDIS funded services. The NDIA should provide information and education for providers to ensure that the role of supported decision-making in the context of accessing services is understood by providers.

This approach protects the rights and interests of the participant and ensures that guardianship orders are not being sought as a 'solution' to the issue of having service agreements signed. For this cohort of NDIS participants, decisions made with support is a practice more in line with the human rights obligation of adhering to the least-restrictive options when engaging services.

## **Recommendation 6**

**The National Disability Insurance Agency's administrative processes should be sufficiently flexible to ensure that participants can implement decisions made with support.**

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<sup>4</sup> Guardianship and Administration Act 2019 (Victoria)