Submission to the NDIS Support for Decision Making consultation

**August 2021**

# **Background**

The NSW Ageing and Disability Commission (ADC) commenced on 1 July 2019. The ADC is an independent statutory body that is focused on protecting adults with disability and older people from abuse, neglect and exploitation, and protecting and promoting their rights. Our roles include:

* responding to allegations of abuse, neglect and exploitation of adults with disability (18 years and over) and older people (65 years and over or, if Aboriginal and/or Torres Strait Islander, 50 years and over) – including by providing advice, making referrals and conducting investigations
* taking further action that is necessary to protect the adult from abuse, neglect and exploitation
* raising awareness and educating the public about matters relating to the abuse, neglect and exploitation of adults with disability and older people
* inquiring into and reporting on systemic issues relating to the protection and promotion of the rights, or the abuse, neglect and exploitation, of adults with disability and older people
* providing oversight and coordination of the NSW Official Community Visitor (OCV) scheme – involving adults living in the care of disability supported accommodation and assisted boarding houses, and children living in residential out-of-home care
* meeting other obligations as outlined in the *Ageing and Disability Commissioner Act 2019*.

The ADC includes the Ageing and Disability Abuse Helpline.

The majority of the reports handled by the ADC relate to adults with disability and older people who are subject to, or at risk of, abuse, neglect and exploitation in their family, home and community (including allegations against family members, spouses/partners, informal carers, and members of the community).

**Decision-making and reports to the ADC about adults with disability**

From the start of the ADC, a key part of our work in responding to reports has related to decision-making. In particular, seeking to uphold the rights of the adult with disability or older person to make their own decisions and have those decisions heard, respected and followed.

Among other things, we frequently identify matters in which:

* adults with decision-making capacity are not being provided with opportunities to make decisions or support to do so (where needed)
* service providers are defaulting to the adult’s family or spouse to make decisions, or automatically upholding the decisions of the family/ spouse, because:
  + they incorrectly believe the family/spouse is the legal ‘guardian’, nominee, or other decision-making authority
  + they incorrectly assume the adult is unable to make their own decisions
  + it is faster and easier to do so – for example, where the adult requires communication support and/or requires other decision-making support
  + the family/ spouse is dominant, difficult, and/or has been making decisions for the adult over an extended period
* service providers and families seek for the ADC to override the adult’s decisions (or to apply to the NSW Civil and Administrative Tribunal for another party to do so) due to concerns that the decisions are not in the adult’s interests – typically involving high risk, such as domestic violence
* the adult’s family/spouse has become their ‘nominee’ with government agencies (such as the NDIA, Centrelink) in questionable circumstances and without adequate rigor in the process.

In addition to the obvious adverse impact on the adult with disability/older person, the above issues also present challenges for the ADC in responding to the reports. For example, we have many cases where the information provided to the ADC about the adult’s decision-making capacity is inaccurate; no mechanisms or supports have been put in place to assist the adult to express their views and be involved in decision-making; and there is no readily identifiable party who could fulfil the role of decision-making ‘supporter’.

# **Feedback of the ADC**

The ADC welcomes the outline and proposed plan of actions by the NDIA to maximise supports for participants to make their own decisions. We are pleased that the NDIA is taking forward and building on the solid report of the Independent Advisory Council of the NDIS on this topic, and embracing the important role that the Agency can and should play in helping to change and lead practice in decision support.

Overall, the ADC supports the positive pathway for reform that is outlined in the consultation paper. The framework and proposed next steps provide the potential to significantly change practice in relation to participant decision-making and support, drive and embed lasting improvements, and influence broader cultural change.

In light of this, and in the context of the work of the ADC, our comments are focused on strengthening the support for decision-making framework and actions to prevent and address abuse, neglect and exploitation of participants in their family, home and community.

**Appointment of nominees**

Section 5 of the existing NDIS Nominees Operational Guideline identifies that participants are presumed to have the capacity to make decisions that affect their own lives, and ‘Appointment of a nominee is justified only when it is not possible for a participant to be assisted to make decisions for themselves.’ However, in the experience of the ADC, this guidance is not consistently implemented by the NDIA.

As noted earlier, the ADC has handled many reports in which an NDIS Plan Nominee (typically a family member or spouse) has been appointed despite the participant having decision-making capacity. In addition to the fact that this denies the right of the participant to make their own decisions, in a range of cases we have found that this has served to facilitate and exacerbate abuse. For example, it has enabled the nominee to (among other things):

* make decisions that are at odds with the will and preference of the participant
* make decisions that benefit the nominee at the expense of the participant
* cancel necessary services and supports for reasons that assist the nominee not the participant – including to reduce line of sight over the participant and the conduct of the nominee; to exert coercive control over the participant; and to prevent the participant from seeking help from staff they know and trust.

In at least four reports about adults with disability that were finalised by the ADC in 2020/21, the subject of allegation was removed as the adult’s NDIS nominee. This was typically action taken by the NDIA following the provision of information by the ADC about the decision-making ability, will and preferences of the participant, and the concerns that had been identified about the conduct of the appointed nominee.

We welcome the intended actions by the NDIA to overhaul the nominee appointment process, including making sure that the decision-making capability of the participant is ‘considered and documented’ before appointing a nominee. However, it will be important to not only consider the participant’s decision-making capability, but to ensure that any appointment decisions are informed by evidence as to the supports that have been provided and implemented to maximise the participant’s ability to make their own decisions. We support the NDIA’s planned actions to implement processes to review existing nominee appointments at key life stages and plan review – it is vital that the appointment is regularly and proactively revisited, and is treated as a temporary measure.

Against the background of the experience of the ADC, we stress the need to ensure that the intended overhaul of the nominee appointment process is informed by analysis of the factors that have enabled the appointment of nominees for participants with decision-making capacity, against existing clear guidance. It is critical that these factors are addressed to prevent recurrence under the new framework/requirements.

Providing opportunities for participants to *safely* communicate their views, preferences and decisions is an important safeguard in relation to abuse, neglect and exploitation. There must be proactive and concerted steps to ensure that participants have regular opportunities to communicate with the NDIA and NDIS services separately – ie: without their informal supporter/‘decision-maker’. This applies across all areas, including in nominee appointment processes (for example, to enable the participant to signal that they do not want that person to be the nominee).

**Proactive and early identification of the need for decision-making supports**

We support the proposed actions of the NDIA to introduce a formal process to identify a participant’s need for decision-making supports at an early point.

In the context of the work of the ADC, we have previously advocated for the NDIA to strengthen its processes for identifying and mitigating risks to NDIS participants at their planning meetings and reviews, including:

* requiring face-to-face NDIS planning and review meetings to be the default option for participants
* undertaking a basic risk assessment as part of the NDIS planning process
* ensuring that the NDIA/ planner is able to confer with the participant alone (or at least without parties that have a vested interest).

Part of the benefit of the above mechanisms, among other things, is the structured and reliable opportunity they provide to better identify participants who require particular support to mitigate risks; to link them with key safeguards; and to identify and maximise their ability to participate in the planning process and decisions that affect them. In this regard, we consider that access to decision-making supports and communication supports should be fundamental components of NDIS plans.

**Building decision-making capacity and accessing quality support**

Providing quality decision-making support that is free of undue influence, is tailored to the needs of the participant, and helps to build broader decision-making capability in the participant, requires an informed approach. We welcome the inclusion in the proposed framework of support, guidance and training for decision ‘supporters’, with a focus by the NDIA on identifying and promoting best practice.

In our view, there is an important – and should be an enhanced – role for the Information, Linkages and Capacity Building (ILC) arm of the NDIS in supporting and building decision-making capacity in relation to participants and their supporters. In addition, we consider that there is a role for the ILC stream in ‘recruiting’ and upskilling others to be able to provide informal or formal decision-making support to people with disability who need this assistance, enabling proactive development of wider decision-support networks.

On a related note, there would be merit in examining options for funding professional decision support for participants who need it. That is, the ability for a participant to be able to engage, as part of their NDIS plan, an appropriately skilled and independent decision-making supporter. In our view, this would be particularly beneficial in situations/ decisions involving higher levels of risk or complexity, and/or for participants with complex support needs.