

Submission to the NDIS Discussion Paper:

Support Coordination under the NDIS

September 2020

1. Background

The NSW Ageing and Disability Commission (ADC) commenced on 1 July 2019. The ADC is an independent statutory body, which is focused on protecting adults with disability and older adults 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 adults (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
- following an investigation, 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 adults
- 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 adults
- meeting other obligations as outlined in the *Ageing and Disability Commissioner Act 2019* (the ADC Act).

The ADC includes the Ageing and Disability Abuse Helpline.

The ADC also has a general oversight and coordination role in relation to the Official Community Visitor (OCV) scheme in NSW. OCVs are independent Ministerial appointees who visit accommodation services where an adult with disability, older adult or child in care is in the full-time care of the service provider, and assisted boarding houses.

1.1 The focus of our submission

While the ADC has a broad remit, our focus is on adults with disability and older people who are subject to, or at risk of, abuse, neglect and exploitation by family members, spouses/partners, informal carers, neighbours and other members of the community.

Given the role of the ADC, our comments are primarily focused on support coordination in the context of:

- actual or potential abuse, neglect or exploitation of adults with disability (NDIS participants) in their family, home and community
- participants living in circumstances involving high and/or increasing risks
- enabling participants' access to timely and person-centred safeguards.

Our comments are also informed by the feedback of OCVs visiting people with disability in supported accommodation and assisted boarding houses. While the engagement of OCVs with disability services is mainly with supported independent living (SIL) providers, they are in a valuable position to identify the quality and progress of the work of support coordinators; their interaction with residents and SIL providers; and gaps in relation to support coordination for people with disability living in residential care.

In relation to adults with disability living in residential care in NSW, in 2019-20, OCVs

conducted:

- 2,337 visits to 1,120 disability supported accommodation locations
- 60 visits to 16 assisted boarding houses.

2. Reports to the ADC about adults with disability

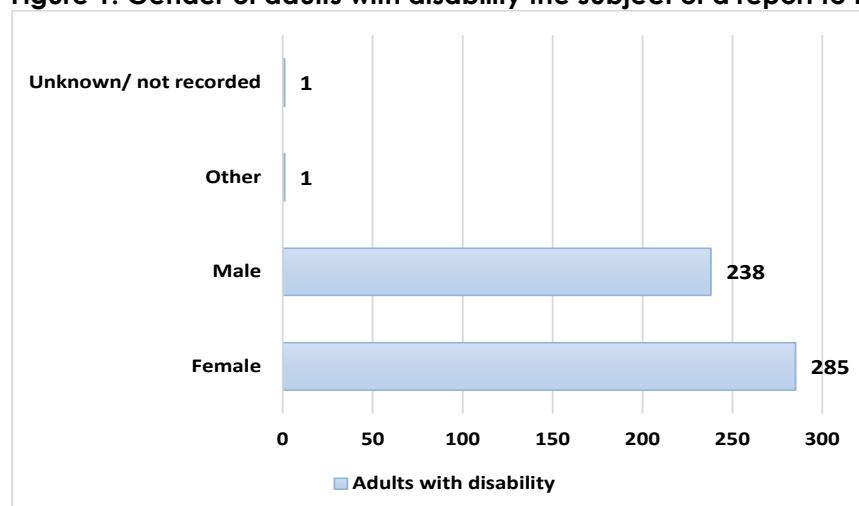
To understand the context of our submission, it is useful to consider the nature of the reports about adults with disability received by the ADC in 2019-20.

In its first year of operation, the ADC received 2,302 reports, including 1,777 reports involving older people, and 525 reports involving adults with disability who were not older people. The following data relates to the 525 reports about adults with disability in 2019-20.

2.1 Gender and age

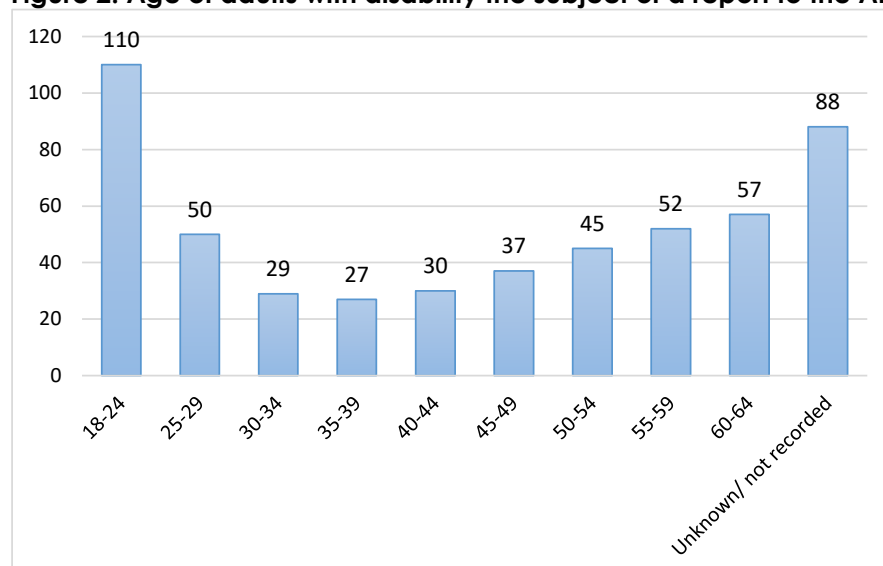
Just over half of the reports (285; 54.3%) involved women with disability.

Figure 1: Gender of adults with disability the subject of a report to the ADC, 2019-20



The largest proportion of reports about adults with disability (21%) involved people aged 18-24 years.

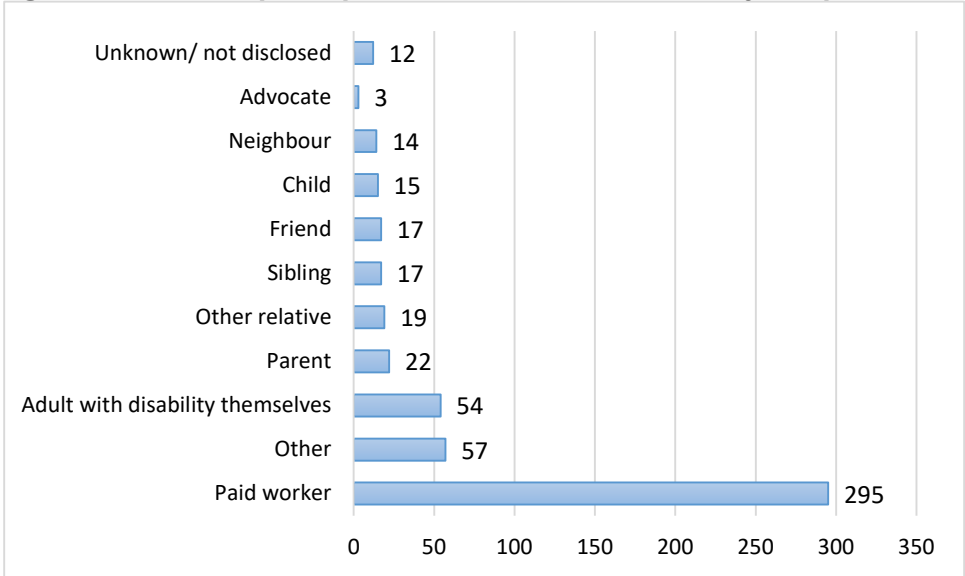
Figure 2: Age of adults with disability the subject of a report to the ADC, 2019-20



2.2 Reporters

Paid workers were the main source of reports to the ADC about adults with disability; primarily staff of disability services. Paid workers were the reporters in over half (56.2%) of all reports received by the ADC about adults with disability in 2019-20.

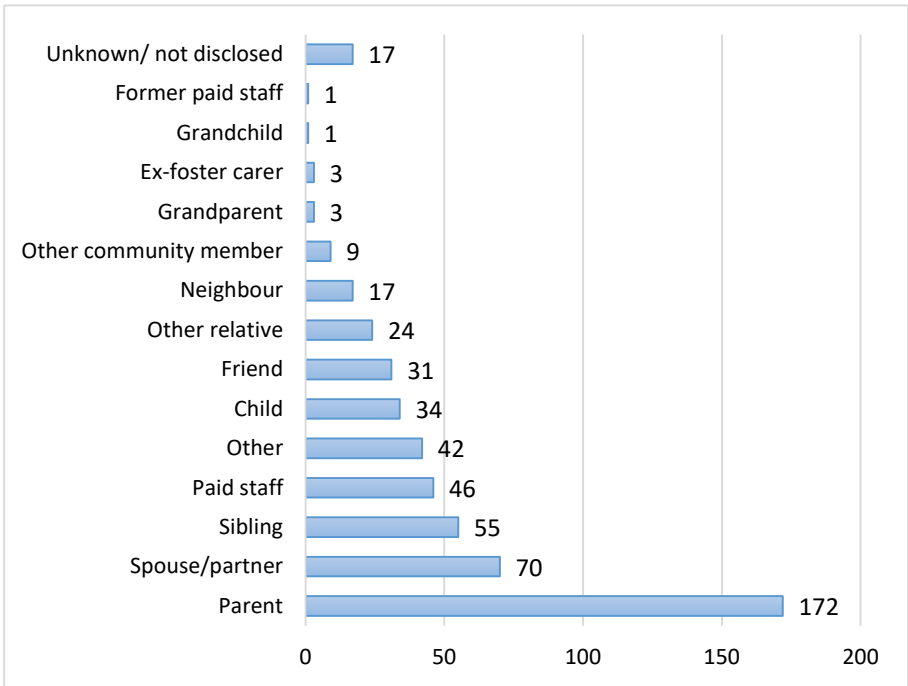
Figure 3: Relationship of reporter to the adult with disability in reports to the ADC, 2019-20



2.3 Subjects of allegation

In almost one-third (32.8%) of reports to the ADC about adults with disability in 2019-20, the allegations pertained to the adult’s parent(s). All up, family members were the subjects of allegation in over half (55%) of all reports about adults with disability. In 13.3% of matters, the adult’s spouse or partner was the subject of the allegations.

Figure 4: Relationship of the subject of allegation to the adult with disability in reports to the ADC, 2019-20



2.4 Type of alleged abuse

Most reports to the ADC involve more than one type of abuse. It is common, for example, for financial and psychological abuse to be reported together, noting that psychological abuse can be applied to gain access to a person's finances.

The most commonly reported types of alleged abuse in relation to adults with disability in 2019-20 were psychological abuse and neglect.

Table 1: Type of alleged abuse against the adult with disability in reports to the ADC, 2019-20¹

Type of alleged abuse	Number of cases	% of all allegations
Psychological abuse (Mainly verbal abuse; preventing or restricting access to supports/services; and preventing or restricting access to family/others; and making excessive or degrading demands)	251	25.1
Neglect (Mainly failure to meet the person's support needs; medical neglect; and failure to provide adequate clothing and/or food)	204	20.4
Financial abuse (Mainly financial exploitation; preventing access to/withholding the person's money; and theft)	168	16.8
Physical abuse (Mainly hitting/kicking/punching; and inappropriate restraint/use of force)	165	16.5
Sexual abuse (Mainly sexual assault; and indecent assault)	63	6.3
Other	131	13.1
Not recorded	19	1.9

3. Key issues and opportunities

3.1 Support coordination is an important safeguard for participants

We agree with the findings in the recent report from the *Review of the National Disability Insurance Scheme Act 2013* (Tune Review) about the value of support coordination – including in helping participants to understand and implement their plan, and reducing the administrative effort required to manage a plan by participants and their families/other informal networks.

However, our work has highlighted significant other tangible benefits from support coordination for NDIS participants who are subject to, or at risk of, abuse, neglect and exploitation in their family, home and community. In our experience, support coordination provides a vital safeguard, particularly for participants in vulnerable circumstances, and in relation to abuse, neglect and exploitation.

¹ The data captures all matters in which that type of abuse has been reported; in the majority of matters, more than one type of abuse is reported.

In our experience, support coordination has assisted participants to be able to leave abusive and/or high-risk situations, and to improve their safety and wellbeing, including by (among other things):

- identifying and reporting actual or potential abuse, neglect or exploitation of the participant, providing supporting evidence, and standing by the participant to assist them to participate
- responding quickly to source alternative short-term or ongoing alternative accommodation
- facilitating access to necessary mobility and communication aids and equipment
- coordinating functional assessments to ensure the provision of appropriate supports to improve the participant's independence and reduce risks
- enabling the provision of additional in-home supports to mitigate risks to the participant associated with the removal of their abusive informal carer.

Example 1

The ADC received a report about a participant with multiple sclerosis being prevented from contact with their family and necessary supports due to the actions of a live-in carer. In the course of responding to the report, we identified that the participant did not have the assistance of a support coordinator.

We made contact with the previous support coordinator, who told us that the participant was unable to speak and did not have capacity to make their own decisions. We subsequently found that this was incorrect, and the support coordinator had formed this view solely based on information provided by the live-in carer, and because the carer always spoke for the participant.

Following our contact with the NDIA, the participant received assistance from a new support coordinator who took swift action to obtain their views and wishes, and to facilitate supports to help them to:

- reconnect with their family after a long period of isolation
- implement new financial arrangements
- move into temporary alternative accommodation while modifications were undertaken to their home to meet their mobility needs
- reconnect with allied health and medical services.

3.1.1 Identifying people who require support coordination

In many cases, we have noted that a participant has a Local Area Coordinator (LAC) appointed, but has not had support coordination included in their NDIS plan. This has included a range of participants in high risk and/or very isolated circumstances, who had a clear need for greater assistance. For example, participants who had an NDIS plan but:

- were not accessing any supports, or were accessing very limited supports (at times, related to the wishes of the family not the participant)
- had a range of support needs that required the involvement of multiple services (with informal carers who were unable or unwilling to coordinate access to the supports)

- had increasing safety and other risks, and no or minimal contact with the LAC or other NDIS parties.

Our work in relation to these matters has emphasised two key points:

1. Support coordination acts as a critical safeguard in a way that local area coordination does not.

In many cases, the ADC has brought the circumstances of individual participants with local area coordination to the attention of the NDIA and identified the need for support coordination. In these matters, we have seen significant changes and improvements following the addition of a support coordinator.

At times, the issues affecting the participant, and need for greater assistance, have been present for an extended period of time – it is only following the report to the ADC and the addition of a support coordinator that actions have been taken to help meet the needs of the participant.

2. Proactive steps ought to be taken to identify participants who require support coordination – at the outset, and at subsequent points.

Our work has identified the need for actions to be taken to better identify and mitigate risks for participants through the NDIS planning process. In our view, it is important to strengthen the NDIA's processes for assessing risks to NDIS participants at their planning meetings and reviews, and to facilitate their access to necessary and person-centred safeguards, including support coordination.

Face-to-face meetings with the participant that include assessment of risk should be part of the NDIS planning process, to ensure direct sight of the person and the opportunity to (among other things):

- Identify participants who are at risk of (or subject to) abuse, neglect or exploitation, or who otherwise may require additional safeguards. In our experience, this includes participants who live in vulnerable circumstances – such as people who are heavily reliant on others for critical activities of daily living; have higher levels of cognitive impairment; have communication difficulties; have complex support needs; are socially isolated; are not involved in decisions that affect them.
- Connect the participant with key person-centred safeguards, such as linking them to a support coordinator rather than a LAC, and ensuring access to communication support.

In addition to information supplied by the ADC and other parties, there should be ongoing efforts by the NDIA to proactively identify participants who may require support coordination (and/or other actions). For example, identifying participants whose funds in their plan are not being drawn down, or only limited aspects of their plan are being implemented or activated.

3.2 Access to support coordination

As noted above, there are opportunities to better and more consistently identify participants who need support coordination at the outset, and at later points. However, the work of the ADC and the OCVs has identified a range of other barriers or difficulties to participants accessing support coordination.

3.2.1 Direct contact with support coordinators

The ADC and OCVs have seen reduced physical contact between support coordinators and participants as a result of COVID-19 and continuing beyond the easing of restrictions in NSW. In some cases, we have identified participants who have not had direct contact with their support coordinator or with other key supports, such as advocates, since the start of the initial lock-down period – exacerbating some of their risks, and making it more difficult to address the reported concerns. Where necessary, we have escalated these matters with service management, and have seen a positive move to recommence personal contact in response. However, these cases raise concerns about the adequacy of the processes by providers and support services to assess risks to participants to inform their response.

We have also noted instances in which the lack of face-to-face contact (in person or via video link) between support coordinators and participants preceded the pandemic. This has included participants who have communication difficulties and have had no other mechanism for communicating with the support coordinator. In some cases, the support coordinator has never met the participant.

It is critical that support coordinators have direct contact with participants and do not default to or substitute a third party for communication – such as the person’s family, spouse, SIL provider, or other.

3.2.2 Delays in gaining access to support coordinators

In relation to participants living in supported accommodation, OCVs have noted delays in their access to support coordinators. In response to concerns raised by OCVs, supported independent living (SIL) providers have provided information about actions they have taken to repeatedly follow-up with the relevant support coordination providers, without success. OCVs have reported that in a range of cases they have subsequently seen SIL providers seek to shift support coordination for the participant(s) to their own service to better manage the process. While this may assist with communication between the support coordinator and the accommodation staff, it raises concerns about the extent to which the participant genuinely has a choice, and the conflicts of interest this presents.

In other cases, OCVs have noted instances in which the participant has not been linked in with supports in their plans, such as community and social activities, as the support coordinator has not been in contact, and the SIL provider has not taken any steps to follow-up or to escalate this with the support coordination provider. In these matters, progress only occurs after the OCV raises concerns with the SIL provider and seeks a response from them about the steps they have taken to resolve the issue.

Example 2

An OCV visits a service that supports residents (NDIS participants) with complex behavioural needs and contact with the criminal justice system. The OCV noticed that one resident had not been out of the house for some time, and did not have any activities in the community. His NDIS plan indicated that he enjoyed art and would benefit from increased social contacts. The plan included strategies to locate an art class in the community and other opportunities for social activities.

The OCV identified that no action had been taken in relation to these strategies since the plan had been approved some months earlier. When the OCV asked the accommodation team leader, he advised that he had not heard from the resident's support coordinator for several months. He had not taken any action to chase this up because he believed that it was not the responsibility of the SIL provider.

The OCV raised the issues in their visit report, which led to the SIL provider making active attempts to contact the support coordinator. It turned out that the support coordinator had left their position. Another coordinator was subsequently engaged, and they began to take steps to locate appropriate services in the community.

The issues identified by the OCVs underscore the need for proactive checks and tracking of plans in which allocated funds for support coordination (and other key supports) are not being drawn down.

3.2.3 Difficulties in maintaining support coordinators

OCVs have raised concerns about the difficulties that some participants living in supported accommodation experience in maintaining support coordinators due to their complex needs. For example, in one house visited by an OCV, the residents had three different support coordination providers during their plans because:

- the first provider said that they could not have a 'working relationship' with the residents
- the second provider closed its office in the area
- the third provider said the support needs of the residents were 'too complex'.

During that extended period, the participants did not receive necessary supports. These matters highlight the importance of the NDIA directly appointing support coordinators in certain circumstances – including where participants are unable to take action themselves to source alternative support coordinators and they are not receiving the support they have been funded for; and/or they have complex needs that require more specialist support.

3.2.4 Others making decisions about access to support coordination

In a range of reports to the ADC, we have noted that the participant has not had access to services and support coordination as a direct result of decisions made by the participant's family or spouse. In particular, in multiple matters we have seen support coordination and other services cease their involvement with the participant following the family/spouse cancelling those supports. In many cases, this is despite:

- the participant having some decision-making capacity and their views/wishes not being sought
- the family/spouse not having any decision-making authority
- the participant having an evident need for support and facing considerable risks
- services having concerns about the decisions of the family/spouse.

In some cases, we have noted that support coordinators solely sought and followed the directions of the participant's family/spouse, or deferred to their wishes, because it was easier and involved less conflict for them. This has included circumstances in which the participant had communication difficulties and no communication assessment or tools had been arranged; and the family/spouse was abrasive and likely to seek to cancel the service if challenged.

The consequences of the above in the matters reported to us can be significant – including that it serves to perpetuate the abuse against the participant; it prevents the support coordinators (and others) from hearing and understanding the experience of the participant and their wishes about the actions they want taken; and it delays appropriate actions being taken, such as involvement of police, domestic violence services, and additional supports.

Our work in relation to these matters has emphasised the importance of ensuring that support coordinators:

- a) directly engage with, and seek direction from, the participant (with appropriate support as needed) – it is critical that support coordinators have a focus on obtaining the views and wishes of the participant and maximising their involvement in the decisions affecting them
- b) provide regular opportunities for participants to speak with them separately/ privately
- c) do not accept cancellation of service when done by a third party without decision-making authority
- d) raise concerns with the NDIA and take other actions as needed (such as making a report to the ADC) where the actions of the family/spouse or other third party are not in line with the wishes/ are against the interests of the participant.

These matters also highlight the need to proactively monitor the plans of higher risk participants so that, if there are actions to cancel support coordination, the NDIA can ensure there is follow-up, including direct appointment of a support coordinator when required.

More broadly, it is important to identify participants whose support coordination funds are not being used or are being under-used, and to examine the reasons. In some cases, it may reflect the choice of the participant and/or a reduced need for support. However, it may also be due to other reasons, including a poor understanding of the role of support coordinators and what they can do (whether on part of participant, family, or the support coordinator themselves), or the participant may be being prevented from accessing support coordination and other supports.

3.3 Quality of support coordination

The ADC and OCVs have consistently noted that the skills and knowledge of the support coordinator make a significant difference to the quality of the support coordination provided and outcomes for participants.

OCVs have seen significant disparity in the skills, commitment and performance of support coordinators across NSW. They have emphasised the adverse impact on participants of poor quality support coordination, noting examples of participants in supported accommodation who have been waiting for months or years for appropriate wheelchairs, mobility aids, assistive technology, functional assessments, and alternative living options, with no evident progress or follow-up by their support coordinators.

The ADC has also witnessed marked improvements in progress and outcomes following a change of support coordinator, including from within the same service.

Example 3

The ADC received a report raising concerns about alleged abuse and neglect of an NDIS participant by their spouse. The participant has an acquired brain injury and mobility and communication difficulties, has considerable health risks, and is highly reliant on support for daily living activities. The participant also has capacity to make informed decisions.

The ADC found that the support coordinator engaged to work with the participant consulted with and deferred to the spouse for decisions, and the spouse signed the service agreements. The participant had very limited access to support, no allied health assistance, limited connections to mainstream services, no mobility aids or equipment, and spent most of their days in bed.

Following a change of support coordinator (within the same service), the participant's circumstances and supports significantly changed. Among other things, the participant was:

- linked to vital allied health supports, including speech pathology, occupational therapy, and psychological support
- able to leave their home for the first time in years
- able to access short-term accommodation to provide a break, enable assessments, and provide a safe space for them to speak about their situation and what they wanted to do
- able to obtain necessary communication tools, including an iPad and a MediAlert.

As a result of the changes, health services re-engaged with the participant to provide ambulatory care to attend to pressure areas and access to specialist consultations. A strong interagency and support network has now been built around the participant, including proactive engagement by their GP.

In our experience, qualifications are not imperative; key common factors associated with high quality support coordinators include:

- a solid understanding of the role of the support coordinator and the breadth of what is possible
- a clear focus and understanding of the needs and wishes of the individual participant
- sound knowledge of possible supports and how to source them
- a creative approach to problem solving
- good organisational skills, persistence and resilience.

There is a need to continue and build on the current work to upskill support coordinators and enhance their knowledge and capacity, including in relation to participants with complex needs.

We also consider that fundamental training for all support coordinators should include identifying and responding to abuse, neglect and exploitation of adults with disability. In this regard, the ADC has recently released a free online training module for direct service staff and volunteers to confidently and competently identify and respond to concerns of abuse, neglect and exploitation of adults with disability and older people in their family, home and community.²

3.4 Managing conflicts of interest

There are evident problems in having support coordination delivered by the provider that delivers other key supports for the participant. OCVs have particularly raised concerns about circumstances in which one provider delivers all supports to the participant – support coordination and all other NDIS funded supports. Aside from the lack of evident process followed by providers to ensure that participants are making informed decisions to engage one provider to deliver support coordination and other services, there are clear conflicts of interest. Among other things, the support coordinator has a vested interest in not looking for alternative accommodation or supports for the participant, irrespective of the participant's wishes.

However, we agree with the Tune Review that changes to manage conflicts of interest in relation to support coordination should not restrict the choice and control of participants. In our view, there are ways to minimise and appropriately manage conflicts of interest, and to check that providers are implementing and complying with those measures. For example, there are proactive steps that could be taken between the NDIA and the NDIS Commission to identify participants whose supports are all delivered by one provider and to examine provider compliance with conflict of interest requirements.

3.5 Importance of information sharing

In the experience of the ADC and OCVs, the operation and effectiveness of support coordination for participants would be improved through better information sharing arrangements.

In this regard, we have noted that there is not always a handover between support coordinators, resulting in duplication of actions, such as re-requesting reports and assessments, and delays in progressing critical steps. OCVs in particular have noted a transient workforce in relation to support coordination for participants living in supported accommodation, affecting the provision, consistency and quality of service to participants. There is a need to ensure that there is a comprehensive handover between support coordinators (supported by thorough record keeping) to better manage this process and ensure that participants are not disadvantaged.

We have also identified that support coordinators do not consistently bring critical matters to the attention of the NDIA to enable an informed response. This includes concerns about NDIS nominees, and actions of parties that present risks to the participant and/or adversely affect implementation of their plan. At times, the ADC has been the only party that has brought matters to the attention of the NDIA, despite the support coordinator also holding this

² See <https://www.ageingdisabilitycommission.nsw.gov.au/tools-and-resources/training/module-one>.

information and noting concerns about the participant's situation.

3.6 Building capacity

It is important to recognise the key role that support coordinators can play in assisting participants to build capacity. The focus in the discussion paper is on the role of support coordinators in assisting participants to make informed decisions. We agree that this is a valuable role, and consider that it should be a core part of support coordination – decision-making support should be a fundamental component of the support coordinator's toolkit.

However, in our experience, support coordinators can also play a critical role in assisting participants to link in with other supports to build capacity, which can help to reduce abuse, neglect and exploitation. For example, linking in with support to develop and strengthen skills to handle their own money – the ADC has seen participants being brought under financial management orders to safeguard their finances, but without evident prior opportunity to learn, test, and build skills in this area. Support coordinators can be an important gateway to participants obtaining this assistance.

Similarly, support coordinators should regularly be identifying participants who could benefit from assistance to help them to build capacity to 'speak up' and raise concerns; to make decisions; and understand and exercise their rights – and helping to link them with this support.