

**National Disability Insurance Agency**

**Submission to: Support Coordination, External Consultation**

Submitted to: supportcoordination@ndis.gov.au

Date: 11 September 2020

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## Introduction

Vision Australia is pleased to have the opportunity to make this submission as part of the NDIA’s review of support coordination services. When it operates effectively, support coordination offers considerable value for participants and assists them to navigate the NDIS process efficiently whilst making the best possible use of their funding and facilitating links with mainstream and community services. There is no question that the provision of support coordination must continue. It is also clear, however, that there is a need to improve the quality of service that participants receive by clarifying aspects of the support coordination role and the functions that it is designed to achieve. Our responses to the questions contained in the discussion paper are set out below. There are four questions to which we have elected not to provide a response as we lack cogent evidence upon which to comment, and the issues dealt with therein are not within scope of our operations.

## Recommendations

* Detailed practice standards should be developed by the NDIA to clarify the role of support coordinators and provide consistency in the quality of services offered across the sector.
* Support coordination funding should be provided in NDIS plans based on an analysis of needs, recognising that there may be key transition points in a participant’s life when support coordination is particularly crucial to allow continuity of services.
* The data regarding utilisation of support coordination funding, as well as utilisation of plan funding generally, needs to be thoroughly explored. There are several factors that may contribute to lower than expected utilisation rates, including episodic use of support coordination services, and the difficulty experienced by participants in identifying a suitable provider of these supports.
* There are indications that participants with plan goals related to education would benefit from more targeted support coordination services, and options to facilitate this should be investigated further.
* While achievement of participant outcomes should be a key benchmark in determining whether support coordination is successful, there are risks associated with pricing that is based on goal attainment. In particular, this may result in goals that are driven by the parameters of the service model, rather than by the participant, thus leading to a potential loss in choice and control, and the capacity for consumer directed support.
* While there is a clear need for conflict of interest policies and the necessary auditing to enforce these, this must be balanced with the ability for participants to select the providers they want to work with. In thin markets, or where low incidence disability cohorts exist, choice of providers is often limited and care must be taken to ensure participants are not unnecessarily restricted in their capacity to access services.

## Submission Questions

### Question 1: What factors should be considered when determining when, if and for how long support coordination should be funded in an NDIS participant’s plan?

Vision Australia is supportive of the general principle that participant need should be the predominant consideration when determining whether to provide support coordination funding. The personal circumstances of participants are complex and varied and as such, the length of time for which they have participated in the NDIS is not the solely relevant indicator of their need for support coordination. The skills and experience of the participant, as well as the knowledge of their families and other key contributors throughout their support network, can significantly influence the level of assistance that is needed.

For participants who are blind or have low vision, one of the key challenges associated with the NDIS is that of accessing information in an accessible and appropriate format. Without access to a variety of information sources, participants who are blind or have low vision are likely to have difficulty in making informed choices about the products and services that will best meet their needs. this is even further complicated if the person has a dual-sensary disability. Many of the clients we work with do not have the level of information access necessary to build and utilise their own community networks, work with providers and research the supports available to them. Support coordinators can play a key role in facilitating access to information, as well as helping participants to build peer networks and establish links with both disability and mainstream services.

A participant’s need for support coordination may also be dictated in part by their location. Participants in metro regions may, for example, be more likely to know others who are accessing similar services, and be more extensively linked in with disability and community organisations. Due to prevalence of low incidence cohorts such as blindness and low vision in remote communities, participants in regional areas often have fewer opportunities to share information with others who have lived experience of disability, and are less likely to have established relationships with service providers.

Support coordination may also be particularly relevant for participants from CALD backgrounds, for whom cultural context and linguistic barriers are likely to inhibit access to information.

Additionally, it is important to recognise that participants with well-developed skills and capabilities may nonetheless benefit from a support coordinator during challenging life transition points, such as relocating to another State or navigating a sudden change in their disability.

### Question 2: Should the current three level structure of support coordination be retained or changed?

Vision Australia is broadly supportive of a tiered support coordination structure, though it is acknowledged that the current three level model is, in some respects, complex and difficult for some participants to understand. A tiered approach does nonetheless reflect the varied needs of participants across the Scheme and allow for adjustments to the level of support provided as their skills and capacity to manage funding independently changes. It is extremely important, however, that participants have mobility to move between the various levels of support coordination funding as their circumstances change. While it is reasonable to expect that participants would move to a lower level of support as their capacity to manage their plan independently increases, it is equally important that they should not be precluded from accessing a higher tier of support coordination in future if their needs dictate that this is required. It is not uncommon, for example, for our clients to experience sudden changes in vision which may mean they require higher than anticipated levels of support for a period of time, or supports that are different from those they would have accessed previously. This is also likely to be relevant for participants with episodic conditions, or disability support needs that do not necessarily remain constant and stable. Any structure applied to the support coordination model needs to be able to reflect the dynamic needs of participants and the development of their skills.

### Question 3: How should support coordination interact with other NDIS supports, for example, local area coordinators, community connectors, liaison officers and recovery coaches?

To date, there has been significant confusion for people with disability, their families and service providers about how local area coordinators, support coordinators and community connectors should interact with one another to support participants. It is also important to recognise that support coordination, as a term, was introduced as a result of the NDIS and it is therefore not a concept that is always well understood. Vision Australia encounters many clients who become confused and distressed as they try to comprehend which individuals and organisations should be assisting them with various aspects of the NDIS process. With the introduction of recovery coach supports under the 2020-21 Price Guide, this complexity in understanding the responsibilities of all the parties who may be involved in working with the participant is only likely to be exacerbated.

Support coordinators should serve as a central point, to assist participants in navigating the Scheme. As a national service provider, Vision Australia sees a high level of variability in the degree to which LACs and planners proactively support participants to understand the funding in their plan. It is common that participants approach Vision Australia seeking services, but have received little, if any information about the funding available in their plan and the ways in which it can be used. Where it is apparent that local area coordinators are not available or willing to offer this support, it often falls to service providers to assist the participant in utilising their plan and understanding their funding. Often, these participants would be better served by receiving appropriate funding for a support coordinator to provide appropriate guidance about plan utilisation and availability of services.

### Question 4: How should support coordination interact with and complement existing mainstream services?

The provision of appropriate mainstream supports is inextricably linked to the capacity to achieve positive participant outcomes under the NDIS. Support coordinators have a key role to play in linking clients with mainstream services and it is imperative that providers of support coordination are able to apply a holistic approach to building a participant’s capacity and identifying products and services that will meet their needs. If the best support identified for a participant is a mainstream service, support coordinators should have a role to play in aiding them to access that support, be it through a community connector, health practitioner, and advocacy service or via other means. Many NDIS participants will experience complexity not just in terms of their disability needs, but also other factors such as housing, challenging family and carer relationships, medical conditions and mental health concerns. While it is not the direct role of the NDIS to address all of these, it is essential that support coordinators have a good understanding of the participant’s life as a whole, so that they can provide accurate information about mainstream supports that are complementary to, and work alongside, the disability interventions that participants access through the Scheme.

### Question 5: What can or should be done to address the level of utilisation of support coordination in plans, and is this any different to general issues of utilisation?

Many of our clients report that they have difficulty in finding a suitable support coordinator. In some regions, this appears to occur because most providers of these supports are already operating at capacity and advise that they cannot accommodate new clients. In other situations, participants state that they have not had the service adequately explained to them or they are simply unable to locate a support coordinator that they feel adequately understands their needs and experience around blindness or low vision. The utilisation data currently provided by the NDIA compares participants with and without support coordination funding in their plans. It does not provide a comparison of utilisation levels for participants with the relevant funding, based on whether they did, or did not, appoint a support coordinator. We would suggest that this issue needs to be explored as part of the NDIA review in order to better understand current utilisation patterns.

Vision Australia would also propose that there is a significant difference between service provision supports, which are more likely to be utilised consistently across a participants plan, versus support coordination services, which may be used more sporadically. It is reasonable to expect that utilisation of support coordination funding will be high during the period of initial implementation of a plan. Once supports have been set up and are operating in a stable manner, however, levels of utilisation might conceivably decrease. Lower levels of utilisation once services are established do not obviate the need for ongoing support coordination funding, as the participants requirements or circumstances might change considerably over the life of the plan, particularly if their condition is fluctuating or episodic. Unlike other supports that are likely to be used consistently throughout the year, there are likely to be spikes of demand for support coordination, depending on how stable the person’s needs are and how well their supports are working for them. If the quantum of funding is reduced based on low or intermittent utilisation, there is a real risk that vulnerable and complex participants may not have sufficient support coordination hours when they need them, thus impacting their access to other services.

### Question 6: What functions should a support coordinator perform? Are there tasks that a support coordinator should not do?

It seems evident that the intended function of a support coordinator is to build a participant’s capacity to design, choose, implement and control their own supports. Support coordinators must therefore be able to provide participants with information, resources and coaching to enable them to make informed choices and understand what is available to them. Ideally, participants should be empowered to the maximum extent possible to make their own decisions and as far as is feasible, choices about appropriate supports should not be made on their behalf by a third party. Support coordinators also have a key role to play in building a participant’s broader support network so as to ensure they have sustainable capacity to engage in supported decision making in the future.

It is clear at present that many participants do not understand the role of a support coordinator, and many support coordinators themselves seem unsure as to how it should operate. We are aware of many support coordinators for example, who only collect progress reports on behalf of their clients, and have no further involvement in plan implementation, or assisting the participant to choose supports. At the opposing end of the spectrum, other coordinators are highly invested in ensuring that participants get the supports they need, by arranging stakeholder conferences, bridging information gaps between support providers to aid everyone in working toward a common goal. The current discrepancy in quality of support coordination could be addressed in part by practice guidance for support coordinators and it is our hope that this will be developed as part of the current review. Equally, clarity of information for participants about the tasks they can reasonably expect their support coordinator to do, and what they will be expected to contribute themselves to ensure the relationship works efficaciously, is essential.

There are indications that some support coordinators take an active role in choosing supports for participants. Some of our clients, particularly families with young children, feel that their support coordinators try to act as arbiters for the supports they access, requiring the client’s chosen service providers to justify why particular programs are needed. Anecdotally, we are aware that some support coordinators take on the role of a substitute decision maker by insisting that clients must seek their permission before funding can be used. This would seem to be at odds with the core function of a support coordinator to build the capacity of the participant. Other participants report they feel support coordinators have forced them into a plan review that they did not really need or fully understand. While support coordinators often provide a valuable service with the potential to significantly improve participant outcomes, these examples demonstrate that it is important to balance this with ensuring they do not undertake a role that fosters reliance or erodes the participant’s capacity to exercise choice and control in selecting and designing their own supports.

### Question 7: Is there evidence that participants with specific plan goals related to education, accommodation and employment would benefit from more targeted support coordination services to achieve these outcomes?

Advice from Vision Australia’s allied health practitioners who work in early childhood and education settings is that support coordinators should play a more active role in providing linkages between supports provided as part of a school setting, and those that are delivered externally as part of broader educational goals in the NDIS plan. There is often considerable overlap between the supports that children receive through the education system and those which are provided outside of school hours. Data from vision assessments conducted in schools could, for example, be used to support children more broadly in their community access an education goals. Currently, this rarely occurs, because assessment results are not shared with families or other service providers. In situations where supports across both education and NDIS are working well for families, this is often because support coordinators are actively involved in seeking collaboration between stakeholders and providing a bridge in the information gap that tends to exist across both systems. It is not a common experience, however, that support coordinators have the level of expertise to consider the holistic picture of a child’s life at this level. Where this does occur, anecdotal evidence indicates that it leads to improved communication between service providers and successful participant outcomes. Consequently, Vision Australia would be broadly supportive of more targeted support coordination options to aid in achievement of educational goals for children and young people.

### Question 8: How could plan management and support coordination be more closely aligned and what would the potential benefits and risks be?

Vision Australia is aware that some of our clients who receive both plan management and support coordination services from the same organisation find this to be a positive experience. Participants and families tell us that they find these relationships less complex to manage overall, and that in accessing both services from one provider, they often feel there is one less organisation that they have to negotiate in their journey through the NDIS. It is important to note, however, that support coordination and plan management require entirely different skillsets. Support coordinators require an understanding of people with complex needs, the various funding and support systems that impact them, and interpersonal skills that can be used to help participants in developing capacity and resilience. Conversely, plan management relates primarily to administration of funding and efficient payment systems. While it is feasible that one organisation could provide both functions, they should nonetheless be conducted by separate groups of staff that possess the relevant skillsets. Similarly, it is reasonable to expect that organisations providing both support coordination and plan management services to participants should not be involved in the provision of their disability support services. Given that support coordination often tends to be provided to particularly vulnerable participants with complex needs, it is important to ensure that they are not subject to undue pressure to access services from a particular provider, and that conflict of interest policies are in place.

### Question 9: Should there be minimum qualification requirements or industry accreditation in place for support coordinators? If so, what might be applicable?

Many Vision Australia clients advise us that the key characteristic they seek in a support coordinator is that of specialist knowledge. While qualifications in disciplines such as social work may be useful because they encourage a holistic view of the person, indications are that participants often value disability experience over and above a formalised certification. Support coordinators with specialist knowledge around blindness and low vision for example, are more likely to understand factors including the value of specialist therapies such as orientation and mobility, the types of assistive technology that may be relevant to the participant and the levels of care or support that they are likely to need. This expert knowledge can then be used to aid the participant in implementing their plan accordingly. Specialist knowledge beyond disability can also be a valuable resource to participants. For example, parents may seek support coordinators with age specific knowledge of early childhood, and Vision Australia has worked with several participants who have sought multilingual support coordinators who can convey information they might not otherwise be able to access. The NDIS is a complex system of funding and it is important that participants are also able to work with support coordinators who can fill their knowledge gaps, recommend appropriate providers and help them to make the most of their plan. Many of our clients and service providers tell us that this level of knowledge among support coordinators is currently poor, with most not understanding the value of disability related therapy, and providing inaccurate advice about plan budgets and how they can be used. While we are of the view that many of the key attributes of a successful support coordinator must be acquired through industry experience, we would be supportive of accreditation or standardised training to help ensure that support coordination providers possess the requisite knowledge of NDIS systems and processes, enabling them to advise and assist participants appropriately.

### Question 10: How can the effectiveness of support coordination be measured and demonstrated?

Achievement of participant goals should be viewed as a key benchmark to determine whether support coordination has been successful. These measures are likely to be qualitative, rather than quantitative, but could include:

* Reviewing the range of supports that participants access. Do they access services from more than one provider, and do they receive a blend of disability and mainstream supports?
* Tracking of goals across plans: As part of a plan review, participants will generally have the opportunity to discuss how they progressed in achieving their goals. In situations where the client has experienced difficulty in working towards a goal, the natural follow-on is to consider whether they have received the right supports. This could also include an examination of how well support coordination relationships are working for them and whether they have been adequately supported to understand and choose appropriate products and services.
* Quality of life measures: Do participants find that working with a support coordinator has enabled them to access different services, think about alternative options and strengthen their social and community participation?
* Capacity building: Has the participant increased in confidence and capability to manage their own supports? And
* Participant satisfaction: Are participants happy with the breadth and variety of services they receive, and with the role support coordinators have played in assisting to implement these?

### Question 13: Should support coordination pricing be determined, at least in part, by based on progression of participant goals and outcomes, and how would this work?

NDIS plans tend to contain broad goals, some of which are also long-term in nature and will not be addressed over one plan period. The key advantage in the broad goals that are used currently is that they are able to be participant driven, providing a high level of flexibility for individuals to decide on the supports, processes and timeframes that will best assist them to achieve their desired outcome. If goal attainment is used as a key measure of pricing, it could reasonably be assumed that those goals will need to be broken down into specific segments that are measurable. There is a real risk that goals will resultantly be driven by the parameters of the service model, and not by the participant, leading to a loss of choice and control. Arguably, this would also create a temptation for support coordination providers to drive or encourage participants towards particular services, regardless of whether or not they are fit for purpose, simply to demonstrate that efforts are being made towards goal progress.

### Question 14: How can a support coordinator assist a participant to make decisions and choices about their disability supports? What are the challenges?

The key role of a support coordinator is to build a participant’s capacity to engage in effective decision making, thereby increasing their choice and control over NDIS supports. One important component of this relates to access to information regarding both disability and mainstream services. Support coordinators have a key role to play in ensuring that participants are able to access information and resources in a format that works best for them. Without a good understanding of the options available to them, participants are unlikely to build the skills to become effective decision makers in their own right. Support coordinators should never take on the role of substitute decision makers and it should be assumed that participants have capacity to direct their own care and support. To that end, support coordinators can, and should, advocate for participants to take charge of considering different support options and choosing those that best meet their needs. In some circumstances, this may mean that a participant chooses options which are different from those that the support coordinator would have recommended. Often, it is important that this be allowed to occur, because it is an essential part of the learning and skill development process and participants should be permitted the dignity of risk.

Support coordinators are also in a unique position to assist participants in building their support networks. All of us, regardless of disability, generally have networks of people that might assist us with decision making, including family, friends, colleagues or trusted advisors. Support coordinators can play a key role in the development of these networks, thereby ensuring that participants have a sustainable capacity to engage in supported decision making into the future.

### Question 15: How does a support coordinator build a participant’s independence, rather than reliance? Should support coordination pricing be determined, at least in part, based on building a participant’s capacity for decision making to become independent?

Support coordinators also have an important role to play, however, in building capacity within the participant’s broader networks, by developing skills of families, carers and service providers. This can be crucial in ensuring that the participant has a series of established tools and relationships that can aid them in supported decision making on an ongoing basis.

 As to whether pricing should be determined based on a participant’s capacity to become independent, Vision Australia is of the view that this would be a very difficult measure to apply consistently. We work with people who are blind or have low vision across all States, Territories, age groups and life stages. The experience of disability is unique for everyone and consequently, the concept of independence can mean vastly different things to each individual.

### Question 16: How can a support coordinator assist a participant in need of advocacy without acting outside the parameters of their role? What are the appropriate parameters of the support coordination role and the personal advocacy role?

By its nature, the support coordination role is likely to involve some level of advocacy support. This might include for example, negotiating with a participant’s service providers to determine what they will offer and at what price. There is also likely to be some crossover between the provision of advocacy support and the support coordinator’s core capacity building functions, for example, when preparing participants for a plan review so that they are able to advocate for their own needs during a planning meeting.

It is important to recognise, however, that not all support coordinators are likely to be skilled advocates. There are, after all, no minimum qualifications for a support coordinator at present, and advocacy is a specific skillset that often takes years for practitioners to develop. It is important, therefore, to provide clarity for support coordinators as to the circumstances when they may need to refer a participant to an external organisation for support. Equally, it is likewise important that participants have a clear understanding of the parameters of the support coordinator role so that they can recognise when additional advocacy support may be required. This aspect of the NDIS landscape is currently quite confusing. Support coordinators can, for instance, assist participants to prepare for a plan review, but cannot be paid from plan funding to attend planning meetings with the participant, as this is considered advocacy support that is beyond the scope of NDIS funding. There needs to be a much clearer definition as to what constitutes advocacy support in the NDIA’s view, so that both support coordinators and advocacy providers can factor this into their service offering and realistically consider the participant needs that they can, and cannot, address.

### Question 17: In what circumstances is it more or less appropriate for a participant to receive multiple supports from a single provider?

The ultimate aim of the NDIS is for participants to receive the supports that best meet their needs, accessed through the provider of their choice. In some instances, it is reasonable to assume that multiple services could be offered via one provider. Providers such as Vision Australia, for example, will often have capacity to meet more than one need for a participant, because we provide multiple therapies that are aligned to their goals, and several allied health practitioners may work in synergy to ensure that therapeutic interventions meet a particular outcome. AS an example, Children may receive services from a physio, an OT a speech pathologist and an access technology specialist to work towards their developmental or educational goals, and where vision impairment is their primary condition, these would often be offered by one provider. Additionally, in regional settings, participants do not always have an extensive choice of providers. Thin markets and low incidence cohorts often mean that Vision Australia is the only provider in a particular area who can supply specialist blindness and low vision services.

Clearly, accessing multiple different types of services from one provider will not always be ideal, particularly where there are indications that participants could be offered greater choice. As demonstrated above, however, this would not necessarily be an automatic cause for concern in every circumstance. It may, at least in some cases, be more effective to look at whether participants are receiving a broad spectrum of supports across both disability and mainstream services, as this could provide an indication of whether they have a robust and comprehensive support system in place.

### Question 19: What impacts would stricter conflict of interest requirements have on NDIS participants and the NDIS market?

In areas where thin markets exist, there is a reasonable risk that stricter conflict of interest requirements may restrict participant access to service providers. This is particularly the case in relation to low incidence cohorts such as those with vision impairment, for whom there is already limited choice of specialist providers with disability specific knowledge and expertise. It should be acknowledged that there are circumstances where it may be appropriate to access more than one service type from a provider and participants should not be unnecessarily curtailed in their capacity to do this where it is considered to be the best option in their particular circumstances.

### Question 20: What would you identify now as the current critical issues around support coordination?

Vision Australia works with many clients across all age groups, life stages and regions within Australia. Overwhelmingly, the feedback that they provide indicates that there is little consistency in the provision of support coordination services. Many of our clients struggle to find a support coordinator who they feel has an adequate understanding of their specific disability needs. Where a suitable support coordinator can be found, participants often tell us that they find the quality of service poor and that there is a high level of variability in the tasks that providers will willingly perform as part of the role. Some support coordinators undertake administration tasks only, such as collecting reports on behalf of participants, and do not engage beyond that level to assist in identifying suitable services and providers to meet the participant’s goals. At the opposing end of the spectrum, others remove all decision making capability from the participant, effectively choosing and vetoing the services they are permitted to access. Many of our service delivery staff also report that they experience extreme difficulty in engaging with support coordinators, despite the client’s wish that they should do so. Requests for information are frequently ignored and correspondence often goes unanswered for months at a time.

When it works well, support coordination offers outstanding value for participants and assists them to navigate the NDIS process effectively whilst making the best possible use of their funding and facilitating links with mainstream and community services. There is no question that the provision of support coordination must continue. It is also clear, however, that there is a need to improve the quality of service that participants receive by clarifying aspects of the support coordination role and the functions that it is designed to achieve. This could be facilitated through the provision of more extensive practice guidance, which would enable both support coordinators and participants to better understand their respective roles and set expectations accordingly. There should also be improved auditing of organisations and an increased focus placed on participant outcomes, to ensure that a uniformly high quality of service can be provided across the sector.

## Conclusion

Vision Australia thanks the NDIA for its consideration of this paper. We look forward to the outcomes of this review and we would be pleased to provide further information in relation to the matters raised in this submission.

## About Vision Australia

Vision Australia is the largest national provider of services to people who are blind, deafblind, or have low vision. We are formed through the merger of several of Australia’s most respected and experienced blindness and low vision agencies, celebrating our 150th year of operation in 2017.

Our vision is that people who are blind, deafblind, or have low vision will increasingly be able to choose to participate fully in every facet of community life. To help realise this goal, we provide high-quality services to the community of people who are blind, have low vision, are deafblind or have a print disability, and their families.

Vision Australia service delivery areas include:

* Allied Health and Therapy services, and registered provider of specialist supports for the NDIS and My Aged Care
* Aids and Equipment, and Assistive/Adaptive Technology training and support
* Seeing Eye Dogs
* National Library Services
* Early childhood and education services, and Felix Library for 0-7 year olds
* Employment services, including National Disability Employment Services
* Accessible information, and Alternate Format Production
* Vision Australia Radio network, and national partnership with Radio for the Print Handicapped
* Spectacles Program for the NSW Government
* Advocacy and Engagement, working collaboratively with Government, business and the community to eliminate the barriers our clients face in making life choices and fully exercising rights as Australian citizens.

Vision Australia has gained unrivalled knowledge and experience through constant interaction with clients and their families. We provide services to more than 26,000 people each year, and also through the direct involvement of people who are blind or have low vision at all levels of the Organisation. Vision Australia is therefore well placed to provide advice to governments, business and the community on the challenges faced by people who are blind or have low vision fully participating in community life.

We have a vibrant Client Reference Group, with people who are blind or have low vision representing the voice and needs of clients of the Organisation to the Board and Management. Vision Australia is also a significant employer of people who are blind or have low vision, with 15% of total staff having vision impairment.