



Submission to the National Disability Insurance Agency

Review- Support Coordination Service Model

September 2020

About Vision 2020 Australia

Vision 2020 Australia is the national peak body for the eye health and vision care sector. Working with and representing almost 50 member organisations, we focus on supporting policy and funding changes to prevent avoidable blindness, enhance eye care delivery and better meet the needs of people who are blind or living with low vision.

Our members span a wide range of areas and are involved in local and global eye health and vision care, health promotion, low vision support, vision rehabilitation, eye research, professional assistance and community support. This means that the work we do in developing sector-supported policy and advice brings a diverse range of expertise and perspectives to bear, and that the perspectives and experiences of both service users and service providers are at the heart of our work.

Avoidable blindness and vision loss in Australia, and our region, can be prevented and treated by working in partnership across government, non-government, private and community sectors. People of all ages who are blind or vision impaired will benefit from these partnerships, with improved access to services that support their independence and community participation.

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Introduction

Across Australia, over 450,000 people are living with blindness and vision loss. These people are at higher risk of a range of adverse health and social outcomes, including double the rates of falls, three times increased risk of depression, four times the risk of hip fractures, greater utilisation of health, aged care and social services, and earlier entry to residential aged care (see Endnote 1).

Vision 2020 Australia members report a range of challenges with current disability support arrangements for Australians who are blind or have low vision. These include:

- Blindness and low vision services are specialist services, and support a relatively small group of participants. This means it is an area at greater risk of thin markets or market failure. As a result, people living in more geographically remote areas can struggle to access what they need.
- Assessors and planners often have limited knowledge of blindness and low vision, what services, training, and support is needed, or how and when participants can access these.
- Current limitations on funding for assistive technology can prevent people accessing the equipment that could keep them more independent, even though this may reduce their need for other services.

One of the findings of the 2019 review of the National Disability Insurance Scheme Act 2013 was that participants “feel the NDIS is too complex and difficult to navigate”. Members believe that due to these challenges, that complexity and difficulty can be increased for participants who are blind or have low vision.

As the discussion paper describes, support coordination was intended to help participants learn to navigate the scheme more effectively. We believe support coordination is uniquely well-positioned to enable people who are blind or have low vision to overcome the unique barriers they face in utilising their plans, and build their capacity to access services independently. However, Vision 2020 Australia’s members are also concerned that due to problems with quality and consistency, the service doesn’t always achieve its aims.

Further, members contend that one of the keys to ensuring an effective support coordination market is clarifying the scope of the role, for both providers and participants.

Inclusion of Support Coordination

Our members are concerned by the comparatively low inclusion rate of support coordination in plans for people who are blind or have low vision. There is significant potential for capacity building in this population, particularly for those who have recently lost their vision. Despite this, the discussion paper shows that people who are blind or have low vision have some of the lowest inclusion rates (29 per cent) of any disability.

One of the barriers to independence for people who are blind or have low vision is their different capacity to access information. This capacity gap can be addressed through a combination of equipment, training, and connection to sources of support.

A person who does not have their access needs met may struggle to independently utilise their plan to solve their problems. This appears to be precisely the kind of gap support coordination was designed to fill. We believe support coordination could significantly increase plan utilisation for this population, and therefore improve their outcomes.

In deciding whether to include support coordination as part of a plan, planners should consider factors such as:

- Thin markets
- Cultural or language barriers
- Whether participants' goals reflect a state of transition
- Recentness of vision loss or change

Members believe that the second and third levels of support coordination remain necessary, acknowledging that the vast majority of participants with support coordination are at the "coordination of supports" level. However, we believe the "support connection" level is similar to the work of local area coordinators (LAC). Given the reportedly high workloads of LACs, perhaps inclusion of "support connection" in a higher number of plans could redistribute some of that work to support coordinators.

Members also suggest that for new participants to the NDIS who have vision loss, support coordination, at least at the support connection level, will likely have a significant positive impact on improving their ability to access their plans. Members are eager to work with the NDIA to explore how a pilot program might evidence the effectiveness, and establish best practice, for support coordination in first plans for people who are blind or have low vision.

While accepting the goal of building capacity, members would also note that people who are blind or have low vision can experience significant changes in their needs as a result of a variety of changes in circumstance. We would therefore suggest that:

1. There are cases in which support coordination may be needed in **later plans** where it previously wasn't required. These do not demonstrate lowered capacity, but may be a result of:
 - a. altered circumstances (episodic needs due to family/home life changes, changes in vision level)
 - b. low plan utilisation
2. There are cases in which the level of support coordination needs to **increase** (e.g. from 1 to 2) as a result of changes in circumstance or problems with plan utilisation. Again, these cases do not imply lowered capacity.

Finally, our members are increasingly aware that First Nations peoples who are blind or have low vision routinely face unique additional challenges, including:

- A form of "double discrimination", as described by the Disability Royal Commission (see Endnote 2), resulting from the intersecting perceptions of minority and disability
- Lack of culturally safe or informed services
- Poor understanding within the NDIA of First Nations culture and community
- Thin markets, particularly in remote or regional areas
- Increased likelihood of experiences of violence, abuse, neglect, or exploitation, leading to lower mental health and emotional well-being (see Endnote 2).
- Lower reported levels of satisfaction with their NDIS plans and outcomes (see Endnote 3)

As a result of all these challenges, our members recommend that support coordination should be included routinely in the plans of First Nations peoples who are blind or have low vision.

Role of Support Coordination

Our members agree that the functions of support coordination need to be more clearly defined by the NDIA. This includes education for both providers and participants about the scope of a support coordinator's role. For example, in some instances support coordinators perform the kind of tasks usually seen in case management roles, particularly at the specialist level.

Similarly, support coordinators are sometimes seen as advocates by participants (see section on 'Building Capacity for Decision making').

All of these preconceptions are partly created by the fact that support coordination is a new role, but also partly by the language used by the NDIA in relation to support coordination. More clarity about what support coordinators should and should not do would likely have significant benefits for the quality and utilisation of the service.

Quality of Support Coordination

The discussion paper raised concerns about utilisation of support coordination in plans where it is provided, as well as how support coordination impacts plan utilisation. Our members believe both of these concerns could be addressed by improving the quality and consistency of the service.

Our members have had interactions with support coordinators who are not well-prepared to deal with the challenges the sector offers. We agree that a minimum qualification or accreditation would likely better position the service to meet its goals.

We acknowledge that creating criteria for support coordination involves balancing the need for recruitment with the need for expertise. However, we believe all support coordinators should be able to demonstrate, at a minimum, a strong understanding of the disability sector, strong interpersonal and communication skills, and grounding in the NDIA's philosophy and priorities.

According to the most recent Aboriginal and Torres Strait Islander participants report, utilisation of NDIS plans for First Nations peoples with disability is 60 per cent, where utilisation for other Australians is 67 per cent (see Endnote 2). Members believe that a significant reason for this is that there is an ongoing lack of culturally safe interfaces via which First Nations peoples can access the scheme.

As previously mentioned, support coordination is a potentially useful mechanism for overcoming the specific challenges faced by this population. But in order to achieve this, support coordinators need to be culturally safe and informed. Vision 2020 Australia suggests that Aboriginal Community Controlled Health Organisations (ACCHOs) are best positioned to provide quality support coordination that meets the needs of First Nations peoples who are blind or have low vision.

The National Aboriginal Community Controlled Health Organisation (NACCHO) has received funding to help support Aboriginal and Torres Strait Islander communities with Community Connectors as part of the National Community Connector Program (NCCP).

Community Connector positions are being established within ACCHOs to provide culturally appropriate advice and access to the NDIS. The National Community Connector Program (NCCP) will go some way to help First Nations peoples access and use NDIS services, but it is time limited 12-month funding, with no option of further funding. More needs to be done to establish permanent supports for First Nations peoples to access and utilise NDIS services

While plan utilisation is one measure of the effectiveness of support coordination, members agree that other methods should be applied. Notably, responsibility for reporting outcomes largely rests with providers, support coordinators, or the agency. A tool which allows participants to reflect on how, and whether, support coordination has helped them to achieve their goals could provide valuable information about the real-life impact of the service.

The discussion paper reveals that where support coordination is not included, plan utilisation is slightly lower for people who are blind or have low vision. We believe this may not be a completely accurate way to measure impact of support coordination for this community, because it includes people at a range of life stages, and with varying capacities.

We believe another useful data set would be comparison of participants' utilisation of their supports and services in plans where they had and did not have support coordination included. This would provide more information about whether support coordination helps specific participants access supports and services, which they otherwise could or may not.

Building Capacity for Decision-making

Our members agree that support coordinators should, wherever possible, teach participants to access services and or supports independently. Essentially, a support coordinator should facilitate a transitional process, at the end of which their services are no longer required. However, support coordinators are largely incentivised to report their continued necessity wherever possible. We believe incentives should be introduced to ensure that support coordinators perform the role the NDIA intends – to build capacity, not dependency.

One of the most significant challenges for support coordinators is the unclear parameters of the role. We accept that clearly, support coordinators should not make decisions on behalf of a participant, but the discussion paper gives the example of helping participants to access supports “during times of crisis or instability, or in areas with an insufficient supply of disability supports”. In both these cases, it is difficult to establish what advocacy is and is not.

Tasks like helping participants negotiate with providers, or assisting with preparation for plan review meetings, also seem to unavoidably require the kind of advocacy which the discussion paper suggests is not currently within the scope of the role. We believe a clearer definition of what advocacy is in the context of this role is essential.

It is possible that advocacy may prove to be an unavoidable element of a support coordinator's work, but our members contend that:

1. Advocating on a participant's behalf should be viewed as a last resort
2. A support coordinator can only advocate for decisions already made by a participant
3. In negotiations involving service providers or the NDIA, a participant is responsible for clarifying their needs and goals. A support coordinator's role is to provide information and evidence to justify a participant's requests or decisions.

Conflict of Interest

Our members support clear and strict guidelines in order to protect participants from instances where support coordinators also provide other services. Within the vision sector however, thin markets in some regions mean the only services available are offered by providers that also offer support coordination. Continued efforts by members and by the NDIA to abolish thin markets may help minimise conflict of interest problems within the sector. Vision 2020 Australia's members contend that:

1. People who are blind or have low vision should not be forced to choose between accessing support coordination and accessing services they have been offered in their plans.
2. Participants should be allowed the choice to use support coordinators who specialise in their disability, even if they are part of an organisation that also offers services they may choose to access.

Recommendations

Vision 2020 Australia believes the critical issues for the future success of the support coordination service model are quality and consistency. These can be improved via:

- A minimum qualification or certification for support coordinators
- Clearer definition of the scope of the role
- Incentives for support coordinators who build capacity in their clients
- Alternative quality measurement systems for support coordination, including self-reflection opportunities for participants, correlation between support coordination and achievement of goals/outcomes rather than plan utilisation.

In relation specifically to people who are blind or have low vision, Vision 2020 Australia's members contend that:

- The 29 per cent inclusion rate of support coordination is too low, given its capacity building potential for this population
- First Nations peoples who are blind or have low vision should routinely have culturally safe support coordination included as part of their plans due to the unique and intersecting challenges they face
- Inclusion of support coordination, or a higher level of support coordination, in later plans does not necessarily constitute reduced capacity or increased reliance
- Any new conflict of interest requirements introduced around support coordination should not threaten a participant's ability to utilise the services in their plan

We look forward to working with the NDIA to help build a more effective support coordination market.

Endnotes

Statistics provided in this report were drawn from the following sources:

1. [Clear Focus – the Economic Impact of Vision Loss in 2009 \(Vision 2020 Australia, 20`10\)](#)
2. [First Nations People with Disability Issues Paper](#) (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2020)
3. [Aboriginal and Torres Strait Islander Participants Report](#) (NDIA, 2019)
4. [Support Coordination Discussion Paper](#) (NDIA, August 2020)