



Improving the NDIS Experience

Establishing a Participant Service Guarantee and Removing Legislative Red Tape

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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 change 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.

By working in partnership across government, non-government, private and community sectors, avoidable blindness and vision loss in Australia and our region can be prevented and treated and ensure that people who are blind or vision impaired of all ages, have equal access to services to support their independence and community participation.

For further information about this submission, please contact Vision 2020 Australia on policy@vision2020australia.org.au or 03 9656 2020.

Executive Summary

The introduction of the National Disability Insurance Scheme (NDIS) under the National Disability Strategy has helped many Australians living with disability and improved their lives. Greater choice and control for people living with disabilities is strongly supported by Vision 2020 Australia's members, and for some people who are blind or have low vision, the NDIS has delivered substantial improvements in their lives. Our sector remains strongly committed to the aspirations of the NDIS and the potential it holds to transform the lives of people living with blindness, low vision or other disabilities.

There are, however, a range of fundamental system design and process issues that could be enhanced to better meet the needs of people who are blind or have low vision. People living with blindness and low vision represent a very small proportion of the overall number of Australians living with disabilities, and very specific assessments and services are required to best support their needs.

The inclusion of principles in a Participant Service Guarantee will be an important first step to provide clear guidelines and expectations for participants and disability service providers. We believe that in addition to the principles listed in the discussion paper, the principle of **flexibility** should be added. This would be significant for participants who are blind or have low vision due to the potentially episodic nature of their condition.

The Participant Pathway Experience has several areas that could be enhanced to make it easier for people who are blind or have low vision to enter the NDIS. For example, the access requirements for vision loss needs to be reviewed, with the aim of including more eye health disorders on Lists A, B and E. To support this the definitions used need to move beyond a narrow medical focus of blindness and expand to consider the functional impact vision disorders can have more broadly.

Planning and planning outcomes are critical to a participant's experience throughout the NDIS. Unfortunately for people who are blind or have low vision, our members tell us that there are times when this process is not working optimally for them. This can be for a number of reasons including: information provided in inaccessible formats, planners and assessors not possessing adequate knowledge on blindness or low vision or not understanding how to provide participants with a safe environment for them to engage in the process.

Unnecessary and unplanned plan reviews can be caused by the creation of sub-optimal plans at the outset, requiring participants who are blind or have low vision to request for, and navigate the review process more often than they should. This creates undue hardship for the participants who may have to re-tell their story and re-explain their symptoms and condition on many occasions to achieve their desired outcomes.

With a few concrete changes and some added flexibility into the system the NDIS could provide a consistently positive experience for participants who are blind or vision impaired. The eye health and vision care sector are committed to working collaboratively with the NDIA and other stakeholders to achieve this objective.

1 Principles for Participant Service Guarantee

Principles for Participant Service Guarantee from DSS discussion paper

| Principles | Descriptions |
|------------------------------|---|
| Timely | The NDIS process will be easier to understand and use, enabling decisions about access, planning and review to happen promptly. |
| Engaged | The NDIA engages with people with disability, their family, carers and other support persons when developing operating procedures and processes. |
| Expert | NDIA staff have a high level of disability training and understand the impact particular disabilities have on people's lives. They understand what supports are most effective for a person's disability. |
| Connected | The NDIA works well with governments, mainstream services (such as health, education, justice services), disability representative groups and providers to ensure people with disability have coordinated and integrated services. |
| Valued | Participants, their families, carers and other support persons feel valued in their interaction with the NDIS, and know where to go if they need further assistance. |
| Merit based decisions | The NDIA acts in a transparent, informative and collaborative spirit so that participants understand why decisions are made. |
| Accessible | All people with disability can understand and use the NDIS, and the NDIS ensures its services are appropriate and sensitive for Aboriginal and Torres Strait Islander people, people from Culturally and Linguistically Diverse (CALD) backgrounds, LGBTQIA+ and other individuals. |

1.1 What principles are critical for the NDIA

All of the above principals could provide important guidance to how the Scheme is administered in a way that gives greater clarity and improved outcomes for participants. Some of the principals are particularly important to participants who are members of the blindness and low vision community.

Three principles that have particular significance to people who are blind or have low vision in the NDIS include:

- **Expert** – Currently people who are blind or have low vision navigating the assessment and planning processes are finding that Local Area Coordinators (LACs), planners and

assessors do not currently possess the level of knowledge required to adequately assess and plan supports and services for this cohort. It is also important to understand that participants are themselves experts on the nature of their disability and needs, it is then critical that their input is equally valued.

- **Connected** – The intersection between the NDIS, Health and Education systems is an important aspect that requires further delineation and review of how the systems can better connect to the benefit of participants. Currently, our members tell us that participants of all ages are not only caught between these policy areas, but impacted by the lack of connection between the service delivery systems. This results in participants missing the critical supports and services they require, in the setting that they require them.
- **Merit based decisions** – Transparency around decision making for the provision of supports and services is a continuing concern for participants who are blind or have low vision. Due to the specialist nature of vision loss participants are occasionally prescribed supports and services that are not the best fit for their needs or desired outcomes, sometimes in opposition to advice provided by the participants specialists.

The blindness and low vision community would benefit from having these principles included in a Participant Service Guarantee. Another principle that should be considered which would have a large impact not only on the low vision community but people with disability as a whole is flexibility.

- **Flexibility** - Participants need to be afforded greater control and flexibility over how funding is allocated in their plan, and the ability to repurpose money in a more timely and effective manner if their goals or circumstances change. Increasing flexibility in NDIS plans will assist participants to effectively and independently manage their own requirements.

A combination of these principles would take an important step towards codifying for NDIS participants what the Scheme is aiming to achieve and what can be expected from the process. Clarifying expectations and deliverables will go a long way to helping alleviate concerns that are currently held by participants.

1.2 How can we measure success?

Success can be measured through closer engagement with both Participants and Disability Service Providers, through quantifiable data collection. The principles will directly affect both participants and providers so actions must be taken to connect with them directly to measure the success of any participant service guarantee.

Some potential actions that could help measure the success of any participant service guarantee:

- Qualitative and quantitative surveys and/or methods of data collection with participants and disability service providers

- Using current National Disability Insurance Agency (NDIA) data, such as the NDIS Participant Outcomes survey, to quantify whether the new principles are generating better outcomes for participants on the Scheme
- Monitoring the degree to which unplanned reviews continue to occur after the principles and strategies have been implemented. Fewer plan reviews would indicate a positive effect of the reforms and improved outcomes for participants.

2 Improving the Participant Pathway Experience

2.1 Access issues for participants

Participants with blindness or low vision can face difficulties when accessing the NDIS, especially children who require timely access to receive critical Early Childhood and Early Intervention Supports. A delay in the planning process, access to services or provision of assistive technology can be dire for participants who may miss critical developmental milestones as a result.

Ocular disorders can be progressive and normally follow a clinical trajectory of deterioration, however there are not enough ocular disorders listed as automatic entry into the NDIS. Instead, children or adults with ocular disorders are required to unnecessarily prove that their conditions will lead to permanent disability and reduced functional capacity, rather than utilising readily available specialist assessments and information from the eye health and vision impairment sector.

2.2 Making access requirements easier for participants to navigate

There are a number of concrete actions that can be taken to ensure NDIS access is easier for people who are blind or have low vision and ultimately a more equitable experience:

2.2.1 Expand the ocular disorders on List A, List B, and List D in the NDIS Operational Guidelines. These lists provide guidelines on what information is needed to enter the Scheme and whether information is needed to support this. A review of the list to include more progressive eye diseases will ensure people are able to enter the Scheme in a timely manner and access capacity building services that will greatly increase their activities of daily living.

2.2.2 The definitions used to demonstrate blindness for entry into the NDIS represents a narrow view of vision loss and does not accurately represent the functional effect vision loss, below blindness thresholds, can create for people. Entrance into the NDIS should place greater emphasis on the functional capacity of the entrant through a low vision assessment, rather than purely clinical definitions and visual acuity measures.

2.3 Transparency around NDIA decision making

Our members tell us that there are instances where decisions about a participant's access eligibility or plan content have been made by the NDIA which is not evidence-based. For example, critical pieces of evidence, provided by eye health professionals which demonstrate the impact of the participants vision related conditions, may not have been considered.

It is understood that the NDIS is a system predicated on participant choice and control, however the constraints of policy and funding guidelines can also be a barrier to participants achieving their goals. The reasoning behind decisions made by the NDIA need to be clear and transparent and explained to participants using their preferred method of communication, in a timely way.

3 Streamlining Plan Creation

3.1 Challenges in the planning process

Our members advise that some participants have met significant challenges in establishing plans, and subsequent supports, that appropriately meet their needs. In some instances, this has resulted in people who are blind or have low vision experiencing poorer outcomes or reduced quality of life compared to their experience prior to the NDIS' introduction.

Participants who are blind or have low vision can have greater difficulty in engaging during the planning process for a number of factors: information provided in inaccessible formats, planners and assessors not possessing adequate knowledge on blindness or low vision and not understanding how to provide participants with a safe environment. This can include participants with vision loss attending planning meetings with planners who do not have the necessary training to safely guide or orientate the participant if necessary, creating an unnecessary and extra stressor.

There have been many examples of both children and adults who are blind or have low vision being unable to access the supports they need because of ambiguities around the intersection between the disability, health and education systems, and which should meet the associated costs. This is causing some participants to face significant delays in receiving the supports and services they require.

For people experiencing progressive vision loss, the delays in plans have sometimes meant that by the time they receive supports they are no longer suitable, a dilemma that currently requires them to immediately commence the cycle again but does not allow their supports to ever 'catch up' to their needs.

The episodic and specialist nature of vision loss requires greater flexibility and understanding in the planning process to ensure that participants who are blind or have low vision receive the best planning outcomes to achieve their goals.

3.2 Transparency in planning outcomes

Vision 2020 Australia members have advised that the process of accessing NDIS and establishing a plan can be as difficult for people with newly diagnosed vision loss as it can for those who have been vision impaired since birth. For people who experience vision loss as an impact of stroke, for example, knowing their immediate support needs or current and future goals may not be possible. People with blindness or low vision, no matter what the cause, require assistance from vision specific service providers when preparing their NDIS plan. This level of support creates greater transparency by assisting participants, the NDIA and service providers with a clear, evidence-based and accurate planning pathway.

The process for plan creation can become murky when LACs and planners do not possess or have access to the required in-depth understanding of blindness and low vision to make best practice decisions on appropriate supports and services. This has led to people with vision loss being refused supports and services that have been recommended by blindness and low vision specialists, without a clear rationale provided by the NDIA. A clear example is the misunderstanding of the role of Dog Guides which are not only a mobility and navigation tool, but a means of increasing capability and confidence in all activities of daily living. The rules around core versus capacity building versus capital budget spending is quite unclear when it comes to the funding of Dog Guides. This is further exacerbated when a Dog Guide is considered 'assistive technology' and funds can only be used for that express purpose. These limitations and lack of transparency and flexibility in the use of funds is largely problematic for participants.

This is potentially further complicated by the ongoing developments in assistive technology that are offering people who are blind or have low vision greater independence than ever before, can be challenging to keep abreast of. Due to this, it is imperative that advice being given by specialists is considered, and if not followed a clear rationale is given as to the reason why.

4 Using and Reviewing Plans

4.1 Issues with plan reviews

Vision 2020 Australia members have advised that plan reviews can be a long process for some participants and can be a source of frustration if they have to occur too frequently due to the creation of an inadequate initial plan.

Unnecessary and unplanned reviews can cause significant stress and issues for participants including:

- Having to continually tell planners and assessors their story can be challenging for participants and can place unnecessary hardship on them, affecting their ability to engage in the process and self-advocate

- The length of time the review process takes, and the lack of information provided on how it is progressing also. creates ambiguity
- Receiving the necessary assessments and information from specialists can be an expensive and slow process, making an unexpected plan review a potentially costly and arduous task.

Unnecessary plan reviews can be avoided by allowing Service Providers with specialist knowledge greater access to participants throughout the planning or review process - this may include a NDIS funded pre-plan/review assessment to ensure the Service Provider has assessed and prepared participants for their planning meeting. Plan reviews should be a streamlined process which causes minimal disruption to the participants lives and service provision.

If, for example, a low vision service provider determines that a participant's goals and/or functional capacity has not changed at the time of review the LAC may decide that a less formal, expedited process could apply. Similarly, longer plans for more stable conditions may also help lessen the amount of plan reviews required, but this will be a decision that should be made by the participant with a mechanism to trigger a review or amendment in a timely manner if circumstances change.

5 Increasing Flexibility for Plan Amendments

5.1 How can the planning amendment processes be improved for participants?

There is not enough flexibility in the current process to allow participants to respond to changes in their functional capacity as they occur. For participants with progressive conditions a full plan review can take too much time and will lead to them missing out on supports and services during critical intervention periods.

Participants should have greater flexibility to repurpose funding allocations in their plans to respond to any changes in their functional capacity until their plan review has been complete. This could include moving money between different areas of support as they require it, without a formal plan review.

Vision 2020 Australia are working closely with the NDIA to determine areas in which the blind and low vision sector can assist with the access and planning processes. This may include input to LAC/planner 'Blindness and Low Vision Snapshot' training; preparing advice on the usual pathways or trajectories for ocular conditions; or assisting with easy to access specialist advice for all LAC's/planners nationally.