

Vision Australia submission

NDIS Supported Decision-making

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Submission approved by: Chris Edwards, Manager Government Relations, Advocacy, NDIS and Aged Care

# Vision Australia submission – NDIS Supported Decision-making

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## Introduction

Vision Australia welcomes the opportunity to provide this submission to the NDIA, regarding improvements to supported decision making and the proposed development of a framework to support this endeavour. We are broadly supportive of the Agency’s increased commitment to ensuring that participants have the right decision-making supports in place, as well as real and meaningful opportunities to build their capacity for choice and control.

## Recommendations

* The NDIA must strengthen its commitment to the provision of accessible information that is delivered in the participant’s preferred format and language, and which has point in time relevance to each phase of the NDIS pathway.
* The NDIA should continue to strengthen the consistency of information available to participants and their supporters, through clear operational guidelines, simplification of funding where possible, and ongoing monitoring of the quality of advice provided by Agency staff and partner organisations.
* the relevance and efficacy of Local area coordinators within the NDIS model should be re-evaluated. There may be considerable benefit in investing in alternative support mechanisms that are better able to meet the needs of participants. Greater access to support coordination could help to address this need, however, it is important that providers of these services are supported by robust guidelines that emphasise the significance of building participant decision making capacity to the maximum extent possible as part of their role.
* The participant’s views as to who is best placed to support them must be of primary importance in any decision-making framework that is developed. Families and informal peer networks can play a key role in this area, however, in the case of low incidence cohorts such as blindness and low vision, it should be acknowledged that service providers often deliver high levels of unfunded decision-making support to participants. This is particularly the case where highly specialised services are needed, but few providers are available to offer them.
* The decision-making framework must work along-side the planning process and be adaptable to a continuum of participants, from those who need no support, through to those who require extensive supports and safeguards to ensure that their needs are met.
* Participants must have opportunities to be involved in decision-making from a young age, as this can assist greatly in the development of self-advocacy skills.
* There should ideally be processes in place to review the efficacy and suitability of the participant’s current decision-making supports. This could take place as part of the regular plan review process, or in response to key life changes such as leaving school, seeking employment, or changes in living situation.
* There should be greater emphasis on exchange of information during planning meetings. The plan review process should be simplified, and there should be greater investment in advocacy services to assist participants through the process.
* There should be a default position of providing support coordination hours to CALD participants as well as those with complex disability needs such as dual sensory loss.
* Where providers are adopting more than one supporting role for the participant, such as that of both plan manager and support coordinator, or support coordinator and service provider, it must be demonstrable that there are strategies in place to mitigate potential conflicts of interest, and that these have been explained to the participant.

## Submission Questions

### Question 1: How can we help people with disability to make decisions for themselves?

There are several conditions that must be in place in order to ensure that participants are able to effectively participate in decision making processes. Firstly, the NDIA must strengthen its commitment to the provision of accessible information that is delivered in the participant’s preferred format and language, and which has point in time relevance to each phase of the NDIS pathway. This is essential in ensuring that participants can understand the choices available to them and communicate those choices effectively. While it has been pleasing to see an increased focus from the Agency on delivery of accessible information in recent times, further work is needed to embed best practice across the NDIA and the various organisations (such as Local Area Coordination Providers), that it contracts to provide services to participants. Without access to clear, sequential and relevant information at each stage of their NDIS journey, from access through to planning and review, participants will be unable to engage fully and effectively in decision-making around their needs, funding and supports.

Secondly, it is important that participants have access to consistent and reliable information. There are often several parties from whom participants may seek guidance around NDIS funding and processes, including NDIA staff, local area coordinators, support coordinators, service providers and plan managers. Where the advice provided is conflicting or inaccurate, this can have significant impacts on a participant’s ability and confidence to advocate for their needs and make well-informed decisions. The NDIA should continue to strengthen the consistency of information available to participants and their supporters, through clear operational guidelines, simplification of funding where possible, and ongoing monitoring of the quality of advice provided by Agency staff and partner organisations. Agency staff and partners should also have a higher level of accountability for the quality of information that they provide.

It is well documented that many participants find the NDIS environment complex and they must therefore have adequate support to understand their plans and the ways in which their funding can be utilised. This is a crucial component in empowering people with disability to be actively involved in the decisions that impact them. 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.

Vision Australia works with a number of participants who struggle to manage support budgets and to understand how they can be used, however, we find these clients rarely have support coordination funding included in their plan, even though they would benefit from it greatly. Several participants have been informed by their planners that they categorically do not meet the relevant criteria to qualify for support coordination funding and will never receive it. This seems contrary to the person-centred focus of the NDIS, where the situation of each participant is considered individually. We are also aware of some participants who are incorrectly told during planning meetings that if they choose to receive support coordination funding, they will have no choice about the providers that deliver their supports.

What is clear is that many participants are not receiving appropriate guidance about the funding contained in their plan and how to utilise it and that service providers are expending considerable amounts of unfunded time to address the shortfall. Careful consideration must be given to the level of support that local area coordinators are realistically able to provide. Current NDIS guidance is that participants should receive up to ten hours of support from a LAC, however, this level of plan implementation guidance is commonly unavailable. In many cases, it appears that local area coordinators simply lack the skills and knowledge to provide it. We respectfully suggest that the relevance and efficacy of Local area coordinators within the NDIS model should be re-evaluated, and that there may be considerable benefit in investing in alternative support mechanisms that are better able to meet the needs of participants. Greater access to support coordination could help to address this need, however, it is important that providers of these services are supported by robust guidelines that emphasise the significance of building participant decision making capacity to the maximum extent possible as part of their role.

### Question 2: Who are the best people to help a person with disability to make decisions?

This is likely to be highly variable, and may depend on a number of factors including the participant’s level of education, social and community engagement, family situation, life stage and cultural background. In some situations, service providers such as Vision Australia provide extensive support to participants in building their capacity to understand NDIS processes and make decisions about their support needs and funding. This may particularly be the case for low incidence cohorts such as vision impairment, where there is a high need for specialised services, but relatively few providers who can offer them. In these situations, service providers can play a valuable role in building the participant’s skills and confidence, and enhancing their capacity to problem-solve and self-identify key supports. Peak advocacy and sector representative bodies can also play an important part in disseminating information and building participant confidence around decision-making.

For many of our client cohort, we find that peer networks, both formal and informal, are invaluable to participants, because they facilitate the sharing of knowledge and information. People who are blind or have low vision can often provide unique support for one another in ways that families, professional service providers and non-disabled peers cannot. It is important that the NDIS provides encouragement for participants to engage in peer networks, outside of formal, goal-oriented group programs, as this can play a key role in building decision-making capacity.

Vision Australia has encountered very few participants who feel that they have been well supported in decision making by local area coordinators and more often than not, their involvement appears to lead to greater stress, frustration and confusion overall. It appears that NDIA partners do not always receive adequate training to identify the level of decision-making support that is needed, particularly in situations where there is dual sensory loss, or where the participant’s needs are complex. As an example, Vision Australia has worked with a Deafblind participant who applied for access to the NDIS. The participant is an adult who lives with his family. His mother communicated to the Local area coordinator during the initial access conversation that the participant was capable of making his own decisions, but would require access to an interpreter to assist with the planning meeting. The LAC stated it must be “awful” to be in the position of the participant’s parent, and suggested it would be “easier” if his mother simply applied to be his nominee, so that he need not be directly consulted about decisions surrounding his plan. The family was extremely upset by this approach and elected not to proceed with their NDIS application.

Some participants may receive decision-making support from family and friends, however, in its quest to maximise the use of informal networks in preference to funded supports wherever possible, the NDIA must not force or coerce participants to rely on friends and relatives where they do not wish to. The participant’s views as to who is best placed to support them must be of primary importance.

### Question3: What should decision supporters do to help with decision-making?

It is important to recognise that those supporting a participant with decision-making may also benefit from capacity building to ensure that they are helping in ways that are constructive, inclusive and respectful. While support from family, friends and others within a participant’s informal network is frequently well-intentioned, supporters do not always have the requisite skills to create opportunities for participants to be involved in the decision-making process, or to distinguish when they are substituting a participant’s decision, versus supporting it. Creation of resources to build the capacity of families, friends and carers will be an important component of any decision-making framework that is developed.

It is also important to recognise that a person’s decision-making capability can change or develop over time. As part of its framework, the NDIA should consider automatic triggers, such as key age points or changes in life circumstances, that lead to a review of current decision- making supports to assess how well they are working for the participant. The decision-making framework must work along-side the planning process and be adaptable to a continuum of participants, from those who need no support, through to those who require extensive supports and safeguards to ensure that their needs are met.

Participants must have opportunities to be involved in decision-making from a young age, as this can assist greatly in the development of self-advocacy skills. Where possible, involvement of children and young adults in the NDIS planning process should be maximised, to help build confidence in articulating needs and wants. The current draft of the NDIA’S Supported Decision Making policy appears to consider this as being significant only for children over the age of 12, however, it should be recognised that even though parents or child representatives will play the primary role in determining supports, for some participants, there may be opportunities to begin building these skills from an earlier age.

### Question4: How can decision supporters get better at helping?

It is important that decision supporters not only provide options to the participant, but that they explain the consequences of those options and allow for dignity of risk where possible. It can be challenging, particularly where supporters have close personal connections with the participant, for them to allow space for making mistakes and exploring possibilities that they might not ordinarily consider.

The NDIA has indicated its intention to create resources, such as factsheets and videos, that give practical examples of best practice decision-making support across various life stages and situations. We consider that this is a positive step forward and will facilitate worthwhile conversations about what effective supported decision-making can look like. In addition to these resources, ILC funding could potentially be deployed to facilitate capacity building in this area for particular cohorts or local communities.

### Question5: How can we make sure the right people are helping? For example, that they are building the capacity of the person with disability and considering what the person with disability wants?

There should be processes in place to review the efficacy and suitability of the participant’s current decision-making supports. This could take place as part of the regular plan review process, or in response to key life changes such as leaving school, seeking employment, or changes in living situation. There must also be clear and independent processes in place to allow participants to notify the NDIA at any point during their NDIS journey, if they feel that their needs and views are not being represented by those who are assigned to support them. Commitments about how and when the NDIA will respond to these requests should be included as part of the participant service guarantee.

In addition, there should be clearer processes to follow in the event that participants do not feel adequately supported by the NDIA or its partner agencies. Anecdotally, we are aware of many participants who are highly dissatisfied with the support they receive from Local area coordinators, however, it is often unclear as to whether the NDIA’s usual complaint processes can be utilised in relation to its partner organisations as well. Participants often identify that they would like to find an alternative local area coordinator to work with, but are unclear on whether they have options to do so.

### Question 6: What should decision supporters know about so that they can help people with disability to make decisions?

Decision supporters must be aware of particular activities or processes that may lead a participant to feel chronically disempowered. Lack of opportunity to access information independently, or being forced into decision-making within unreasonable timeframes, are key examples of this. In the case of formal decision supporters, such as Agency partners and support coordinators, it should be noted that the quality of these supports can have significant impacts on the ways in which participants make decisions. There may be value in increased training and operational guidelines for support coordinators, to ensure that they are functioning in an environment and structure that maximises decision-making capability of individuals. Formal supporters must have a holistic understanding of the participants they work with, including any boundaries or limitations on their capability and the broader networks of peers, community groups and providers that they may want to consult with as part of their decision-making.

### Question 7: Can you tell us about a time when someone helped a person with disability to make a big decision? What worked well? What could have been better?

Vision Australia Client case Study:

Participant A is legally blind and has received services from vision Australia for several years. She has been an NDIS participant for two years and has a strong understanding of her own personal goals and support needs.

The participant recently underwent an assessment with vision Australia for home modifications to improve her independence in the home environment. Home modifications were recommended and subsequently declined by the NDIA. The participant’s LAC explained the outcome of the assessment, but unfortunately, provided incorrect information. The participant was told that an internal review would not be needed and that she could simply provide additional justification to the Agency. The participant worked with her therapists and treating professionals to provide additional evidence, as advise by the LAC. Several months later, the participant had not received an outcome for the assessment. The participant contacted the NDIA and was advised that the additional evidence submitted could not be found because the correct process for a plan review had not been followed. The participant was told her LAC had provided incorrect information to her, which was directly responsible for the delay. The participant contacted Vision Australia several times to advise that she was confused about what the LAC had done, the information provided to her and the options available. Vision Australia contacted the LAC with the participant to establish what had occurred to date and to help break down the complex information provided. Vision Australia also supported the client to speak with the NDIA and work through available options. The participant was happy with the decision-making support she received from vision Australia, but distressed by the considerable delay in obtaining an outcome from the NDIA. Several Vision Australia staff spent unfunded time in resolving the issue, at no cost to the participant.

The following would have improved the NDIS experience for the participant:

* The NDIA could ensure that all LACs and delegates provide consistent and correct information to participants, guardians and nominees about their options to review a planning decision.
* Information should be communicated to participants and their supporters in a way that is easy to understand and avoids complex terminology or jargon.
* Participants should always be included in any communications about them. For example, if a LAC is contacting a delegate about a participant’s concerns, the participant should also receive this communication.
* The NDIA should be transparent about the timeframes involved in making a decision once a review has been submitted.
* LACs and delegates should be directly accountable for the information they provide.
* Participants should be asked whether they understand the information that they have been given, and provided it in another format if needed.
* Clearer information should be provided on the NDIS website about decision-making processes.

### Question 8: What is the best way to support people with disability to make decisions about their NDIS plan? This includes decisions about using or changing their plan.

There should be a greater focus during planning meetings on provision of information, so that participants have a clear understanding of the options available to them. It is often the case that planning meetings are highly focused on gathering information from the participant, with result that there is little time remaining to ask questions or explore a variety of possible funding and support options. Moreover, due to the frequently overwhelming nature of the planning meeting, it is important that there are subsequent opportunities for participants to ask questions. At present, there are few, if any, additional opportunities to review information before it is submitted for planning approval. If planning delegates require further detail, it is generally obtained from the local area coordinator, and not from the participant, meaning that the participant’s needs are not always accurately or appropriately represented. The majority of local area coordinators are not trained or skilled advocates and this tends to reflect in resultantly poor planning outcomes.

In the event that NDIS plan changes are needed, the current review process is often intimidating and difficult for participants to navigate. It is seldom clear at the outset as to why funding for particular supports has been declined, with the result that participants rarely have clarity as to the additional supporting information they may need to provide as part of a review. It is suggested that the plan review process should be simplified, and that there should be greater investment in advocacy or customer care services to assist participants through the process.

Many participants within vision Australia’s client cohort identify that they receive little to no implementation support once their plan is received. Frequently, this means that participants are unsure about how to use their funding and many find that they are several months into their plan before they have appropriate support structures in place. This creates further stress and fear for participants that their supports will be reduced or withdrawn in future plans if they have not been fully utilised in the requisite timeframe. Given that, as identified in question 1 above, local area coordinators are seldom able to provide any implementation support, it is often left to participants themselves to identify those who can assist them to make decisions and choose suitable providers and services. We respectfully suggest that the efficacy of Local area coordinators should be reconsidered, and that there should be greater focus on developing robust and properly funded support coordination services in their place.

Where support coordination funding is provided, there should be greater emphasis on capacity building around decision making, with support coordinators provided with practical resources and operational guidelines to indicate how this can be measured and achieved.

### Question 9: Are there different things to consider for people with different disability or cultural backgrounds?

In cases where participants have a dual sensory loss, this inevitably leads to additional complexities in communication, understanding and service needs. There should perhaps be a default position of offering support coordination hours to these participants, in recognition that they may be required to work with several specialist providers with differing areas of expertise, in order for all of their disability needs to be met.

It may also be worthwhile to offer additional support coordination hours to CALD participants, particularly those who have recently relocated to Australia and may not be intimately familiar with its Government systems and processes, as well as available avenues of support. Care must be taken to ensure that, where CALD participants need interpreting and translating services throughout the NDIS process, that these parties are not unintentionally relied upon as quasi decision-makers on the participant’s behalf.

### Question 10: How can we help reduce conflict of interest?

As a general principle, activities such as support coordination should be carried out independently of service provision. This reduces the potential for conflict of interest caused by providers recommending their own services in preference to others, irrespective of whether they best meet the needs of the participant. Where providers are adopting more than one supporting role for the participant, such as that of both plan manager and support coordinator, or support coordinator and service provider, it must be demonstrable that there are strategies in place to mitigate potential conflicts of interest, and that these have been explained to the participant. If the participant has the same provider in more than one supporting role, there should be a regular and independent review, to ensure that the participant is confident that these supports are working well and that they are not being unduly influenced in their choices and decisions.

### Question 14: Do you have any feedback on our proposed actions in appendix C of this paper?

Goals 1 and 3 of Appendix C to the consultation paper each state that materials created to support decision-making will be available on the NDIA website, in a variety of formats such as factsheets and videos. The NDIA should actively commit to ensuring information is accessible as part of these goals. Large print, Braille and accessible electronic formats should be specifically stated as a minimum, and equal access to video materials with captioning and audio description available.

Participant satisfaction concerning support from the Agency and its partner organisations should also be included as a key measure of success in relation to the policy reform under goal 1.

Appendix C also references creation of specific support materials for participants, carers, providers and professionals. Support coordinators should be listed as a key subgroup within this framework, as they have a pivotal role to play in supported decision-making.

## Conclusion

Vision Australia thanks the NDIA for its consideration of this paper. We would be happy to provide additional information about any of the matters discussed 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.

We also operate Memorandums of Understanding with Australian Hearing, and the Aboriginal & Torres Strait Islander Community Health Service.