Disability Advocacy and the National Disability Insurance Scheme

# Introduction

The National Disability Insurance Scheme (NDIS) was welcomed in 2013. Its purpose was to realise a human rights based disability support system that would offer people with disability choice and control around the reasonable and necessary supports they need in order to live an ordinary life.

nstead of a streamlined scheme focused on individual need, what we have ended up with is some complicated operational guidelines and legalistic procedures that make the system very difficult to understand and navigate, particularly for people with complex support needs.

The onus falls on people with disability to put their support needs into NDIS language, but much is lost in translation. So who can assist when misunderstandings arise and who can step in when things go wrong?

This information sheet shows where the role of Disability Advocate intersects along the NDIS journey and how this role differs from those of Local Area Coordinator and Support Coordinator.

DARU acknowledges the Traditional Owners of Country and pays respects to Elders past and present.

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# Who does what in the NDIS?

**Participants:**

* Are people with disability with a current NDIS plan.
* Use their plans to purchase supports that align with their areas of life goals such as independent living, community participation and capacity building.

**Local Area Coordinators (LAC):**

* Help people with disability gather the evidence they need to complete an NDIS Access Request.
* Assist participants to establish goals and support them through the planning and plan implementation process.
* Provide information about mainstream supports to both participants and people with disability who are not eligible for the NDIS.

**Support Coordinators:**

* Help participants connect to NDIS and other supports.
* Build a participant’s capacity and capability to understand their plan, navigate the NDIS and make their own decisions.
* Broker supports and services in line with a participant’s wishes and their plan budget.
* Monitor plan budgets and support effectiveness.

**Disability Advocates:**

* Act, speak or write to promote, protect and defend the human rights of people with disability on an issues basis when their rights have been breached or denied.
* Are independent. They sit outside of the NDIS and disability service systems.

# How are the roles funded?

**Disability Advocate:**

Funded variously by state and federal government programs as a free service for people with disability.

**Support Coordinator:**

Funded by participant plans (only plans with a Support Coordination budget can access a Support Coordinator). They may be sole traders or work within disability service provider organisations.

**Local Area Coordinator:**

Funded community partners through NDIS contracts for all people with disability - not just NDIS participants.

“Advocacy is not well defined - it’s not really written anywhere about what we do, and when we would step in. We get a lot of referrals from the LACs to help with access requests, but from our understanding, it’s their role to support people to access the NDIS.” - Advocate

# The NDIS Journey - Who can help?

## Applying for the NDIS

A person with disability must first complete an Access Request form in order to become an NDIS participant. Evidence, such as a diagnosis and functional capacity assessment, is needed to support the Access Request.

|  | Disability  Advocate | Support  Coordinator | Local Area  Coordinator |
| --- | --- | --- | --- |
| Q: Who can help a person with disability apply for the NDIS in the first place?  Can provide information and resources. | Individual advocacy can be provided in situations of extreme outreach where the person has no informal/ formal supports to assist. | Not applicable because Support Coordinators are only available to existing NDIS participants. | Will respond to any queries arising during the completion of the Access Request and can assist with referrals to relevant professionals for diagnosis and functional capacity assessments if required. |

Note: Even if the LAC has assisted with the Access Request, they have no say in the decision about whether the person is rejected or deemed eligible. This is done by the NDIS.

|  | Disability  Advocate | Support  Coordinator | Local Area  Coordinator |
| --- | --- | --- | --- |
| Q: If a person’s access request is rejected but they still need support to access the local community and other government programs, who can help them? | Can assist with providing support and information regarding appealing the NDIS decision that rejected their application and deemed them ineligible. | Not applicable. | Helps all people with disability to connect with mainstream community services within information Linkages and Capacity Building (ILC), and other relevant government programs. |

## Planning

Eligible NDIS participants are invited to attend a planning meeting where their support needs and goals will be discussed. Sometimes the resulting approved plan isn't quite right - specific therapy or support that were discussed at the planning meeting have not been included, or some supports have been allocated with insufficient budget attached.

Tip: Ensure that Support Coordination is included, particularly for a first plan.

A participant has the right to review a plan. The first step is an internal review where the NDIS will consider the participant’s requested changes. They may incorporate the changes or decide that the original plan was right. If the participant disagrees and is still unhappy, the next step is an Administrative Appeals tribunal (AAT) review.

|  | Disability  Advocate | Support  Coordinator | Local Area  Coordinator |
| --- | --- | --- | --- |
| Q: The participant is not happy with their plan, who should they talk to? | Can support and provide information to submit an internal review of a decision. AAT reviews can only be undertaken by specifically funded NDIS Appeals advocates.\* | May also help to submit a request for an internal review of a plan if the participant chooses to use their Support Coordinator to complete this task. May also assist to complete the AAT application form. However may not provide representation at the AAT and bill for services, except under extreme circumstances where permission is granted by the AAT and NDIA. | Can provide information and guidance about the internal review and AAT review processes and finding relevant forms. Can also assist to initiate the internal review process if a person verbally makes this request or sends an email. |

\* Appeals advocate finder is available on the DARU and Department of Social Services websites.

## Plan implementation

The participant is happy with their plan and it’s now time to start purchasing the reasonable and necessary supports. Note: For plans that do not include Support Coordination, the Local Area Coordinator will take on that role.

|  | Disability  Advocate | Support  Coordinator | Local Area  Coordinator |
| --- | --- | --- | --- |
| Q: Who can help a participant to start using their plan? | Can provide information and guidance to direct a participant to their Support Coordinator and LAC. | Helps participants to build capacity and competency in using their plan by explaining the supports that can be purchased under the different categories and translating goals into billable hours. | Ensures that the participant's plan is available in their preferred format and helps them to "understand it. Also provides access to the My Place portal, where to find information about their plan and track their budget. Undertakes to build capacity and competency in using their plan if participant has no Support Coordinator." |

## Plan review

|  | Disability  Advocate | Support  Coordinator | Local Area  Coordinator |
| --- | --- | --- | --- |
| Q: Who can help participants with sorting out their arrangements with service providers? | Assists when a participant needs to address a specific issue with their service provider, or initiate a formal complaint process. | Uses local knowledge to best match supports and services in line with a participant’s plan budget, wishes and preferences, as well as monitor service agreements and service bookings. | Assists participants to connect to services if they are not able to do this themselves, or if they do not have Support Coordination and need a list of local  providers. |

Participants specify the plan duration for 1 year, 2 years or, in some instances, up to 5 years. At the end of the period, the plan comes up for review.

|  | Disability  Advocate | Support  Coordinator | Local Area  Coordinator |
| --- | --- | --- | --- |
| Q: The participant’s plan is about to end and needs to be reviewed. Who can help prepare for this? | Provides information and support if participants aren't happy with the new plan and need assistance with either an internal review or an AAT appeal to get the desired changes included. | Collates an evaluation report to demonstrate how effective supports have been against the stated goals to take to the plan review meeting. | Notifies participants when their plan review is coming up and will book a time and place of mutual convenience to conduct the plan review where any "changes to the plan will be discussed. If an evaluation report is not available, assists participants to gather other evidence of plan effectiveness such as reports from treating practitioners." |

“I think we need to be very clear about this - the Support Coordinator’s role is purely and simply to link the client in with services that are reflected in their plan. But they are doing the advocacy work that we are funded for, and there’s no way that the Department can identify that level of advocacy on behalf of Support Coordinators.” - Advocate

|  | Disability  Advocate | Support  Coordinator | Local Area  Coordinator |
| --- | --- | --- | --- |
| Q: The participant’s budget is running low before the planned review date. Who can help get it topped up? | Assists when a request for plan review has been denied or Change of Circumstance application is unsuccessful and the decisions need to be appealed. | May assist participant to complete a Change of Circumstance form if directed to do so by the participant. Note that the Support Coordinator will need to manage potential conflict of interest, particularly if more Support Coordination funding is being requested. | Initiates a Change of Circumstance or Plan Review once this request has been  communicated by the participant in an email, by phone call or by completion of a Change of Circumstance form. |

|  | Disability  Advocate | Support  Coordinator | Local Area Coordinator |
| --- | --- | --- | --- |
| Q: The participant has been caught in an unexpected crisis and needs help fast. Who can help? | Assists when access to crisis services (which may involve justice, education, familyviolence, or health) is being denied, or rights to be free of abuse and discrimination are not upheld. | Works with participants to establish disaster and emergency plans and takes action to implement them if the need arises (which may include connecting with services outside of disability support services). | Becomes involved when crisis triggers a Change of Circumstance and adjustments to plan budget are urgently required. |

# What Disability Advocates don’t do

Request for advocacy in the NDIS has increased dramatically in recent times but many referrals are inappropriate. Here are some common ones that demonstrate why.

“With service agreements, we’ve pushed back reminding them that signature is not required. There’s uncertainty about engagement of advocates, of advocacy roles. Service providers make assumptions that we are there to make decisions on behalf of people, and that needs some attention and clarity.”

- Advocate

**Q: My client needs their Service Agreement signed. Isn’t it the role of an Advocate to sign on a person’s behalf?**

A: No. The NDIS Act says that participants should be provided with the support needed to make and implement their own decisions. Only in circumstances where this is not possible, a Plan Nominee is appointed, in writing, to act on behalf of an NDIS participant.

A plan nominee can be an informal support (someone who knows the participant well) or a formally appointed Guardian or Administrator, Supportive Guardian or Supportive Administrator or an Attorney.

**Q: My client has just got a new Behaviour Support Plan that needs an independent person to sign off on it. Is this something an advocate can do?”**

A: No. An independent person in this instance is described in section 134 of the Disability Act 2006. The role specifies that the independent person must communicate the plan to the person in a way that they understand.

Ideally this would be someone who has spent a lot of time with the person and knows them well and understands how they communicate (particularly if this is non verbal).

Given the issues based nature of advocacy, it is unlikely that an advocate would have had the time to establish the necessary communication channels to fulfil the requirements of the role satisfactorily.

**Q: I’m finishing up with my client because they have used up all their Support Coordination funding. Can an Advocate fill this gap until the next plan review?**

A: No. The LAC should be alerted to the situation, and it is then their role to assess the situation and bring the next plan review date forward or to initiate another appropriate internal process. An Advocate would only step in if this process falls down.

**Q: My client needs decision support and has no informal supports in place and doesn’t have a Plan Nominee. Can your advocacy organisation provide this?**

A: No. Advocates are not decision supporters. The right to decision support was formalised in the legislation review of Victoria’s Guardianship and Administration Act in 2019. But the practical application is still catching up. There are currently no independent decision support services available in Victoria outside the authorised roles specified in the Act.

Leadership Plus is offering a pilot decision support program to support people with disability to engage with the NDIS. The purpose is to ensure that people who have limited decision making capability have maximum support in making the many decisions required when accessing the Scheme and obtaining a plan from the NDIS.

“A lot of people have the mindset that we’re an unpaid service of theirs, we’re not costing anything out of their NDIS plan. The burden can be put on us because they think it’s cheaper for us to do stuff than to take money out of their plan.” Advocate