

Immunodeficiencies and Applying for The NDIS

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Acknowledgment of Country

IDFA would like to acknowledge Aboriginal and Torres Strait Islander peoples as Australia's First People and Traditional Custodians. We value their cultures, identities and continuing connection to country.



Introduction to the NDIS

The National Disability Insurance Scheme provides support to people with disability, their families and carers. It is jointly governed and funded by the Australian Federal Government, and participating state and territory governments.

The NDIS was introduced across Australia from July 2016 to ensure people living with a disability can maintain their independence and social and economic participation. It provides reasonable and necessary supports, including early intervention supports for participants, and helps enable people with disabilities to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports.

To access this scheme, you will need to meet eligibility criteria (to the right) and undergo an assessment of the impacts of your functional disability.

Six domains are also used to assess the impacts of your functional disability. In your application you will need to outline the impact of your disability on; communication, social interaction, learning, mobility, self-care and self-management. Supporting evidence is also required to show how your disability impacts on your activities and life.

It is also important to note that the NDIS doesn't just include supports that are funded through the scheme, but also explores

mainstream supports. These are supports outside of the NDIS that already exist and could also benefit participants. These include; doctors, community groups, sporting clubs, support groups, and libraries and schools.

The NDIS also ensures that approved funding will compliment but does not replace these existing informal supports. The NDIS considers preserving your informal existing supports as very important. The only time the NDIS will consider funding for extra support to take over any informal supports, is if your informal supports are no longer able to continue assisting and supporting you or the person living with a disability.

NDIS eligibility criteria includes:

- ✓ Under 65 years
- ✓ An Australian citizen
- ✓ A permanent resident or protected special citizen category visa holder
- ✓ Have a disability caused by a permanent impairment
- ✓ Require disability-specific supports to complete daily life activities and;
- ✓ Show evidence that supports provided now with reduce need in the future aligns with the NDIS early intervention model.



Difference between the NDIS and the NDIA

The NDIA stands for National Disability Insurance Agency which is the government organisation that implements and manages the NDIS, where the National Disability Insurance Scheme (NDIS) is the national funding scheme managed by the NDIA.

The NDIS provides access to individualised and life-long access to funding once you have access to the scheme. The NDIS is described as an 'insurance' scheme because it provides lifetime support – not 'as needed' support, such as in welfare schemes.

Purpose of the NDIS

The purpose of the NDIS is to ensure people living with disabilities have the same level of independence and capacity as people living without disability. This means NDIS can fund things like support workers to assist with accessing the community activities, personal care, domestic assistance, and accessing appointments. This support can also be in the form of allied health supports, as well as exploring therapies like occupational therapy, physiotherapy, psychology, speech therapy, etc.

Importantly, the NDIS is built around a person-centred model allowing the person living with disabilities to exercise choice and control over all the supports they access and who delivers these supports.

If you live with an immunodeficiency, the NDIS could potentially assist you to improve your quality of life through funding to help you to access the community safely, avoid heavily trafficked options like public transport, and even support you to run errands.



Acronyms

Common acronyms you will come across when in the NDIS space include:

NDIS:

National Disability Insurance Scheme

NDIA:

National Disability Insurance Agency

LAC:

Local Area Coordinator

ARF:

Access Request Form

AAT:

Administrative Appeals Tribunal

AT:

Assistive Technology

ADL:

Activities of Daily Life

NGO:

Non-Government Organisation

SIL:

Supported Independent Living

SDA:

Specialised Disability Accommodation

SC:

Support Coordinator

IDL:

Improved Daily Life

PM:

Plan Manager

STA:

Short Term Accommodation

MTA:

Medium Term Accommodation

SW:

Support Worker

SLES:

School Leavers Employment Service

DES:

Disability Employment Service

COS:

Change of Situation

RORD:

Review of Reviewable Decision



Accessing the NDIS

Age

To be able to access the NDIS you need to be under the age of 65. Early intervention for children is from 0 till 9 years old. Once a child reaches 9 years they are assessed to see if they are eligible for the full scheme. If, however, a child is diagnosed with global developmental delay they will be assessed at age 7 to see if they are eligible for the full scheme. This is because by this time they should have received another diagnosis.

Citizenship

To access the NDIS, you need to either be an Australian citizen, permanent resident or protected special citizen visa holder.

Diagnosis

To be able to access the NDIS you need to have a formal diagnosis of a disability that impacts your daily functioning.

Requiring Support

To assess eligibility for the NDIS people living with a disability are required to ask their treating doctor to assist with filling out an Access Request Form. You are also required to provide any evidence in the form of supporting documentation to show the NDIS how your disability impacts your daily functioning.

If you live with a Primary Immunodeficiency, you may particularly benefit from support through the NDIS if you:

- Currently have or need a carer for daily activities.
- Feel that specific assistive technology or support could help increase your independence.
- Have a disability related to organ damage or other impacts of a late diagnosis.
- Could benefit from early intervention to assist to prevent the level of deterioration you may otherwise experience.

If you are diagnosed with multiple conditions, it is important that you and your treating doctor identify the primary condition that most impacts your described functional disabilities. This may or may not be an immunodeficiency depending on your personal experience of your diagnosed conditions.



Evidence of Functional Impacts

To access the NDIS you need to be able to provide evidence of possible functional impacts if you live with a Primary Immunodeficiency.

On the following pages are some general examples of the types of functional impacts you may wish to explore in your supporting documentation, if relevant to your lived experience.

Social Interaction:

Excessive need for sleep (chronic fatigue, feelings of tiredness/weakness) which reduces your capacity to independently and effectively engage with community/informal supports.

Due to symptoms of disability (e.g. Chron's, diabetes, pain, effects of infusions, infections), you need to have access to facilities to meet your needs which negatively impacts on your level of social engagement.

Panic Disorder/Depression (co-morbidities) which significantly impacts your capacity to; engage in social interactions, build social networks and participate in your community.

Brain fog, infections and fatigue which impacts on your ability to engage in social activities at the same level as your peers, specifically for children.

Communication:

Chronic Infections in ear/throat etc which impacts your ability to speak, hear or understand others.

Brain fog impacting on your ability comprehend information and undertake activities.

Reduced capacity for non-verbal communication due to ongoing pain/fatigue.

Overstimulated by symptoms of panic or depression which impacts your capacity to communicate.

Learning:

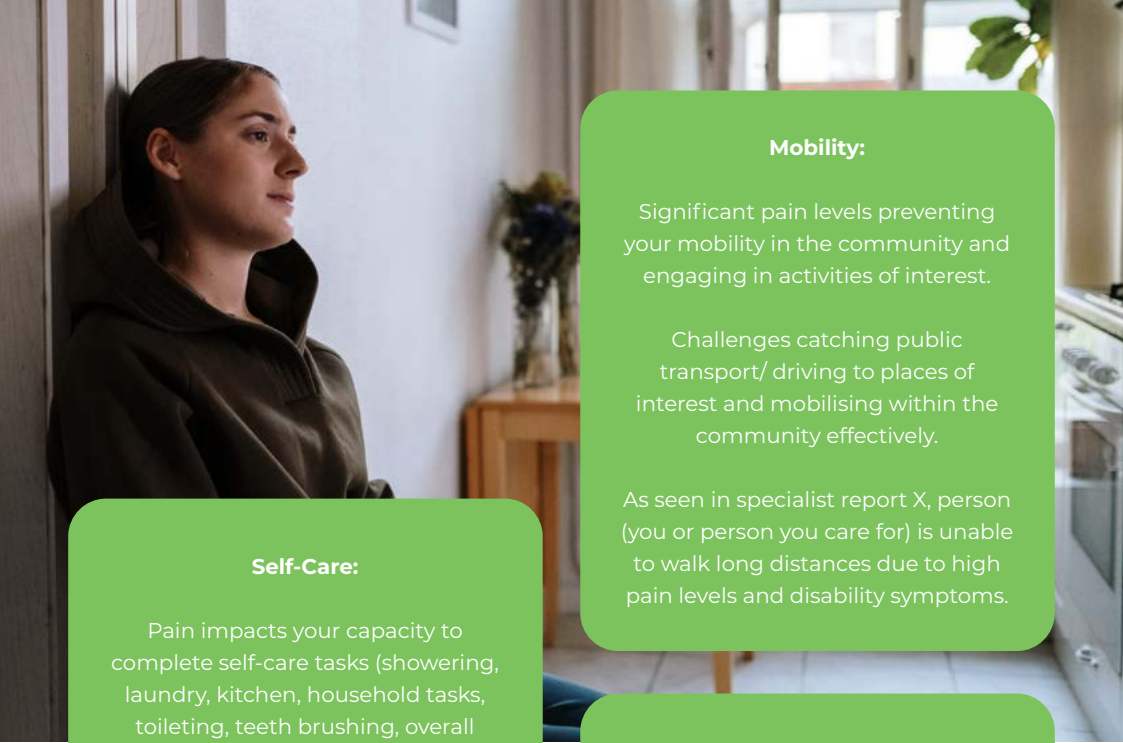
Brain fog/Disorientation which sporadically impacts your memory and ability to take in new information.

Any medication side-effects which can impact your memory, concentration or attention.

Brain infections which significantly impact your capacity to learn new skills and hinders the process of completing educational tasks.

Migraines which impact on your ability to focus and effectively learn new information.

Brain fog/infections/fatigue which impacts your ability to focus and learn new things, specifically for children.



Mobility:

Significant pain levels preventing your mobility in the community and engaging in activities of interest.

Challenges catching public transport/ driving to places of interest and mobilising within the community effectively.

As seen in specialist report X, person (you or person you care for) is unable to walk long distances due to high pain levels and disability symptoms.

Self-Care:

Pain impacts your capacity to complete self-care tasks (showering, laundry, kitchen, household tasks, toileting, teeth brushing, overall hygiene etc.)

Difficulty maintaining an appropriate diet due to malnutrition/ malabsorption due to your disability. Additionally, due to symptoms of pain/panic/depression/heart condition/Chron's you are unable to engage in effective physical activities impacting your health care routines and increasing your isolation.

Debilitating infections which prevent you completing your self-care routines and chores to be completed. When infections and resulting symptoms are present, you require outside supports to manage and continue to complete baseline tasks.

Breathlessness and impaired lung function impact your capacity to complete daily tasks.

Self-Management:

Unable to attend household tasks effectively or manage the build-up of organisational tasks due to your symptoms of chronic fatigue, excessive pain and brain fog.

Booking and maintaining appointments with both formal appointments and friends and family is intermittent due to symptom flare ups, unexpected infections or significant pain/swelling of nerves/organs. This can result in increased isolation or missing important appointments, and strains on informal relationships.

Unable to administer treatments like SCIg due to poor manual dexterity, lack of carer support and hospital infusion visits are not practical.

Client Impact Statement

If you would like to provide additional information from a personal standpoint, you can put together a personal impact statement.

This can be written by yourself, or anyone who provides you with support and care in your network (e.g. family or friends). This type of letter can outline how your Primary Immunodeficiency or other condition impacts you on a day-to-day basis including your ability to work, study and participate in community activities.

It can be beneficial to write about your worst day and what types of support you typically need on these days. This is not required for an application but can provide the assessor with insight into your life. This supporting letter does not need to be extensive and can be formatted in the way you choose.

An example of this type of letter is provided below:

To NDIA,

RE:

Name _____

NDIS Number (If known) _____

DOB _____

Address _____

My name is _____ and I am writing this letter to support _____ application to the NDIS. I have known _____ for _____ year/s.

- This letter would ideally include your personal experiences and information about yourself.
- Add a component outlining times when you have experienced/seen impacts in the categories listed above (communication, social interaction, learning, mobility, self-care, self-management).
- A description of what your day looks like, and examples of limitations of things you might like to do but have thus far been unable to.

If you require any further information, please contact me on _____

Signature _____

Presenting Evidence of Treatments

The NDIS application also asks your treating doctor to list evidence of treatment options that you have already tried.

If the doctor also lists some beneficial treatment options not yet trialled, the NDIS will advise you to try them before considering becoming a participant of the NDIS.

This is because these treatments may change your functional impacts in the long-term and you may not need the NDIS. The NDIS is considered to be a life-long scheme to access supports for long-term needs unable to be met through medical and informal support options. An example of a treatment evidence table is presented below:

Medication, Treatment or Intervention <i>(includes non-pharmacological supports)</i>	Date Started	Date Ceased	Effect on the Impairment				
			Effective	Partially Effective	Not Effective	Unsure	Not Tolerated

Who can assist with evidence?

When applying to access the NDIS there are a range of people that can assist with providing supporting information to assist with your application.

You can ask your General Practitioner, Allied Health Professionals, Specialists or Geneticist. You can also ask any nurses and doctors working within the state or territory health department and non-governmental organisations, as well as support workers.

Sometimes an impact statement from a parent/carer can assist with the application as well to show that a parent/carer is requiring extra support for their child to manage their disability.

Submission

Once you are ready to submit your evidence and information, you can do so by emailing the NDIS at nat@ndis.gov.au or alternatively you can attend your local NDIS office.

Your local office can be found at: [ndis.gov.au/contact/locations](https://www.ndis.gov.au/contact/locations) and adding your post-code in the search bar.





Access not met – What next?

If you apply for the NDIS and are declined access to the NDIS, there are some options you can explore to try and gain access.

You can go for a review of a reviewable decision. This is where someone else from the agency looks at your application and determines if they agree or disagree with the original decision.

You can resubmit an application and include more information and evidence on how your disability affects your daily function enough to the point of needing extra support. This is usually done after speaking with the NDIS and finding out why you were declined so you know what specific information is needed.

You can access the AAT if you have gone through the review of a reviewable decision process and your application is again declined. This then goes to the tribunal and a third party is involved to advocate on your behalf to gain access. You may be required to pay for attending medical or other professionals providing supporting evidence.

The final option is to explore other mainstream options that may be beneficial for you or the person receiving care. Not all people living with a disability will require the support of the NDIS.

Access met – What next?

If you or a person you care for meets the NDIS eligibility criteria, you will be contacted by a Local Area Coordinator (LAC) to book your first planning meeting. At this meeting, you can choose who you would like to attend with you. At your first planning meeting you will discuss:

- What your goals are for the foreseeable future. Often these can be linked to the types of support you may need. For example, *“I would like to build my fine motor skills to be able to participate in an art group”* which may link to engagement with an occupational therapist. Your LAC will assist you to develop these goals to meet your specific needs.
- Discuss how your disability impacts you on a daily basis. It can be beneficial to think about your worst day and what support you may need to assist you on these days.
- Discuss what informal and mainstream supports you have in place, for example your family, friends, health, school etc.

After this meeting your first plan will be released. This will provide you with information of what supports have been deemed reasonable and necessary to meet your needs. LACs do not approve your plan. This is done by the NDIA.

Your LAC, or support coordinator if approved, will then be able to assist you to link in with providers in your area to start accessing supports.

You can locate a LAC for your region here: [ndis.gov.au/understanding/ndis-each-state](https://www.ndis.gov.au/understanding/ndis-each-state)



Further Information

Local Area Coordinators (LACs) can help you to:

- Find practical information relevant to you including information about disability, your rights and online supports and services.
- Understand and access the NDIS. This includes workshops or talking to you about the NDIS.
- Create a personalised NDIS plan once the NDIS has approved your application. Your LAC will talk to you about your current situation, supports, and goals to help develop your plan.
- Implement your NDIS plan. Your LAC can assist you to understand and use the supports in your NDIS plan to help you achieve your goals. The LAC may also be your NDIS contact person to discuss any questions you have about your plan.
- Do a plan reassessment. Your LAC can check-in with you during your plan, to see how you are going and if the plan is working well for you. They can help you make changes to your plan with a plan reassessment or plan variation.

(NDIS, 2023, LAC Partners in the Community)

NDIS Contact Details:

Phone: **1800 800 110**

Email for enquiries: **enquiries@ndis.gov.au**

Email for new NDIS submissions:
nat@ndis.gov.au

To find your local office and attend in person:
[ndis.gov.au/contact/locations](https://www.ndis.gov.au/contact/locations)

NDIS Application and Review Forms:

'What is an Access Request Form?':
[ndis.gov.au/how-apply-ndis/what-access-request-form](https://www.ndis.gov.au/how-apply-ndis/what-access-request-form)

'Request a review of a decision':
[ndis.gov.au/participants/request-review-decision](https://www.ndis.gov.au/participants/request-review-decision)

References:

[ndis.gov.au](https://www.ndis.gov.au)

Thank you to Mandy Drain, Director and Specialist Support Coordinator at Taylor Made Outcomes, for contributing to this Practical Series content.

Our Vision

A future where all immunodeficiencies are diagnosed and treatment commenced early, enabling those impacted to lead productive and fulfilling lives.

Our Purpose

Creating awareness of all immunodeficiencies, supporting and advocating for improved outcomes for patients, carers and families.



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