Rare Disease Disability Toolkit

rare voices
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NDIS and Rare Disease Disability
Part 1: Access and Eligibility

Introduction

This guide is part of the nationally co-designed Rare Disease Disability Toolkit (the Toolkit). It is intended for people living with rare disease disability, their families, and caregivers to use when their eligibility to the National Disability Insurance Scheme (NDIS) is being assessed.

The guide helps people to understand NDIS terminology, describe their condition and support needs clearly, gather appropriate evidence, support health professionals in writing effective letters, and advocate with confidence. It also includes practical information for healthcare practitioners preparing reports and supporting documentation for NDIS applicants or participants.

Toolkit development was codesigned with people living with rare disease disability and facilitated by Rare Voices Australia (RVA). The Toolkit was funded by the Australian Government through the Peer Support and Capacity Building grant for the NDIS.

This resource is accurate at the time of publishing (February 2026). The information provided does not necessarily represent the views of RVA or imply endorsement. RVA is not liable for any loss, damage, or consequences arising from the use or misuse of this resource.

What Is a Rare Disease?

A disease is a condition with a specific pattern of clinical signs, symptoms, and findings, and is considered rare if it affects fewer than, or equal to, 5 in 10,000 people[1].

Rare Disease Disability

Nearly all of the estimated 2 million Australians living with a rare disease experience long-term impacts daily – impacts that meet the Australian Government's definition of a disability[2,3]. The disability impacts of living with a rare disease often aren't recognised by policymakers. There are at least 7,000 known rare diseases, with new diseases being discovered regularly.

To address the challenge of responding to more than 7,000 different rare diseases, RVA has created the following 5 broad rare disease disability categories:

1. **Neurological/neurodevelopmental** – conditions that affect the brain, nerves, or how the brain develops.
2. **Progressive/degenerative** – conditions that get worse and more serious over time.
3. **Episodic/fluctuating** – the impacts come and go, and can change from day to day.
4. **Children with delayed development** – children who take longer to learn and do things.
5. **Undiagnosed rare disease conditions** – there is currently no name or explanation for the condition.

A disease is rare if it affects less than

5 in 10,000 people

There are

7,000+

rare diseases

An estimated

2 Million

Australians live with a rare disease

A Rights Based Approach

This guide considers the following rights and legislation:

- Australia's human rights obligations including under the United Nation's Convention on the Rights of Persons with Disabilities[4]
- The Australian Disability Strategy[5]
- NDIS Code of Conduct [6]
- Relevant NDIS legislation, rules, operational guidelines and policies.
- NDIS Quality and Safeguards Commission rules, guidance and Practice Alerts and Standards that relate to quality and safeguard requirements.

How to Use This Guide

The NDIS can feel complex and overwhelming. This guide includes:

Guide

- Navigating the NDIS with Rare Disease Disability – Part 1: Access and Eligibility – this provides an overview of relevant NDIS legislation with resource links and references. It includes a glossary of key NDIS phrases for rare disease disability.

Checklist

- Checklist – NDIS Letter of Support for Health

Letters for Health Professionals

- **Guidance - Writing a Letter of Support for Rare Disease Disability** (coming soon)

Contents

Understanding Rare Disease Disability in the NDIS

People living with rare disease disability, including those with undiagnosed conditions, may be eligible to access the NDIS and receive ongoing NDIS Supports. However, a rare disease diagnosis on its own does not guarantee NDIS access. This is because rare diseases can lead to very different types and severities of functional impairment, and NDIS eligibility is based on the impact on everyday functioning, and not a diagnosis alone.

NDIS Eligibility Requirements

Eligibility for **initial NDIS access** needs to be proved – **either through the Early Intervention Pathway or the Disability Pathway.**

The NDIS may also ask you to provide evidence to support your **eligibility to continue** to access NDIS Supports if:

- You originally met the Early Intervention requirements, and the NDIS needs updated information about your condition and/or your current functional impairments, **or**
- The NDIS does not have enough information on record to confirm your ongoing eligibility, **or**
- Evidence suggests you may no longer meet one or more of the residency, disability, or early intervention requirements.

Key NDIS Eligibility Criteria

The NDIS has specific criteria regarding eligibility. This NDIS Eligibility Checklist guides you through the process.

To access the NDIS, individuals must:

- Be under 65 at the time of application.
- Be an Australian citizen, permanent resident, or hold a Protected Special Category visa and live in Australia.
- Meet either the disability or early intervention eligibility requirements or both.

Permanent Disability Requirements

To meet the criteria for **disability** eligibility, you must show that the **impairment**:

- Is likely to be **permanent** (i.e. enduring in nature and persisting across the person's lifetime).
- **Substantially** reduces functional capacity to undertake daily activities.
- Affects the ability to socialise, work or study **in some way.**
- Cannot be remedied by any **known, available, and appropriate evidence-based treatments.**
- Is likely to require NDIS Supports through the NDIS **for your lifetime.**

You must also show that all reasonable treatment options have been explored, trialled or discounted and they are either not relevant, available, accessible or appropriate. This includes treatment such as physical therapy, psychology, diet, exercise or other lifestyle interventions.

Early Intervention Requirements

To meet the **early intervention** eligibility, you must provide evidence of the following:

- An **impairment**, or **developmental** delay (for children under 6 years).
- That early intervention supports are expected to **reduce the need for** disability supports in the future.
- That early intervention supports are likely to **improve, maintain, or prevent decline** in function.
- The supports are **most appropriately funded by the NDIS**, rather than by other service systems such as health, education, or community services.

Early intervention supports can be critical for people living with diagnosed and undiagnosed rare diseases. Many rare diseases are complex, progressive or variable conditions, and early support can help maintain social and/or work participation, strengthen family support networks, and reduce the impact of functional decline over time.

As the NDIS focuses on functional impact rather than solely a diagnosis, clear evidence showing **how early intervention will benefit** the person is essential. This includes information from health professionals, carers, and other supports who understand the day-to-day challenges the person experiences.

Early Childhood Approach

The NDIS Early Childhood Approach (ECA) supports children under nine (9) who have a disability, developmental delay or developmental concerns. It provides early intervention, information and connection to services, and assistance with NDIS applications where appropriate. This approach was previously called Early Childhood Early Intervention (ECEI).

Children with a diagnosed or suspected rare disease disability may meet the early intervention requirements if they are:

- Under the age of nine (9) and diagnosed with a **disability** (one or more impairments likely to be permanent), **or**
- Under the age of < six (6) and diagnosed with **developmental delay** and suspected of having a rare disease even if testing (i.e. genetic and/or metabolic) and assessment are pending.

The NDIS criteria for determining **developmental delay** means the child:

- Has a mental and/or physical impairment or both.
- Shows a substantial reduction in functional capacity compared with peers of the same age.
- Requires interdisciplinary care (specialists from two or more professions working as a team) for more than 12 months.
- Needs support across multiple activities, in multiple natural settings (home, community and early childhood centres).

Evidence must be provided from an early childhood professional who knows the child, such as an early childhood educator, child health nurse or allied health professional.

A Note on Global Developmental Delay:

Global Developmental Delay can only be diagnosed by a paediatrician. It indicates significant delay across several areas of functioning and commonly precedes a future diagnosis of disability.

To apply for NDIS access, please refer to the NDIS website - How to apply.

The following pages explain each aspect of eligibility and show how to present strong evidence to support an application.

What Is Good Disability Evidence?

Good evidence for NDIS access can include:

- An NDIS Supporting Evidence Form, **or**
- An NDIS Evidence of Psychosocial Disability Form.
- Statements from the individual, their family/caregivers, describing how the condition affects their daily life.
- A Functional Capacity Assessment Report.
- **A NDIS Letter of Support – Health Professional.** (coming soon)

Gathering Evidence

People living with a rare disease frequently endure a prolonged ‘diagnostic odyssey’, including multiple specialists, repeated tests, and misdiagnoses, before receiving a definitive diagnosis, if one is available at all. Because of this, **functional evidence over time** (e.g. regression logs, episodic fatigue records, educator or therapeutic observations) is often more informative than diagnosis alone for NDIS access. Good evidence should show **patterns across months/years** and in **natural settings** (i.e. home, school, community), not just clinic snapshots. These can help inform assessments and provide evidence for how and why early intervention supports may help.

First Nations Families and Rare Disease Disability

Aboriginal and Torres Strait Islander families may encounter additional barriers to diagnosis and disability supports (i.e., access in remote communities, cultural safety, fragmentation). When preparing evidence or planning supports, First Nations people with rare disease disability can:

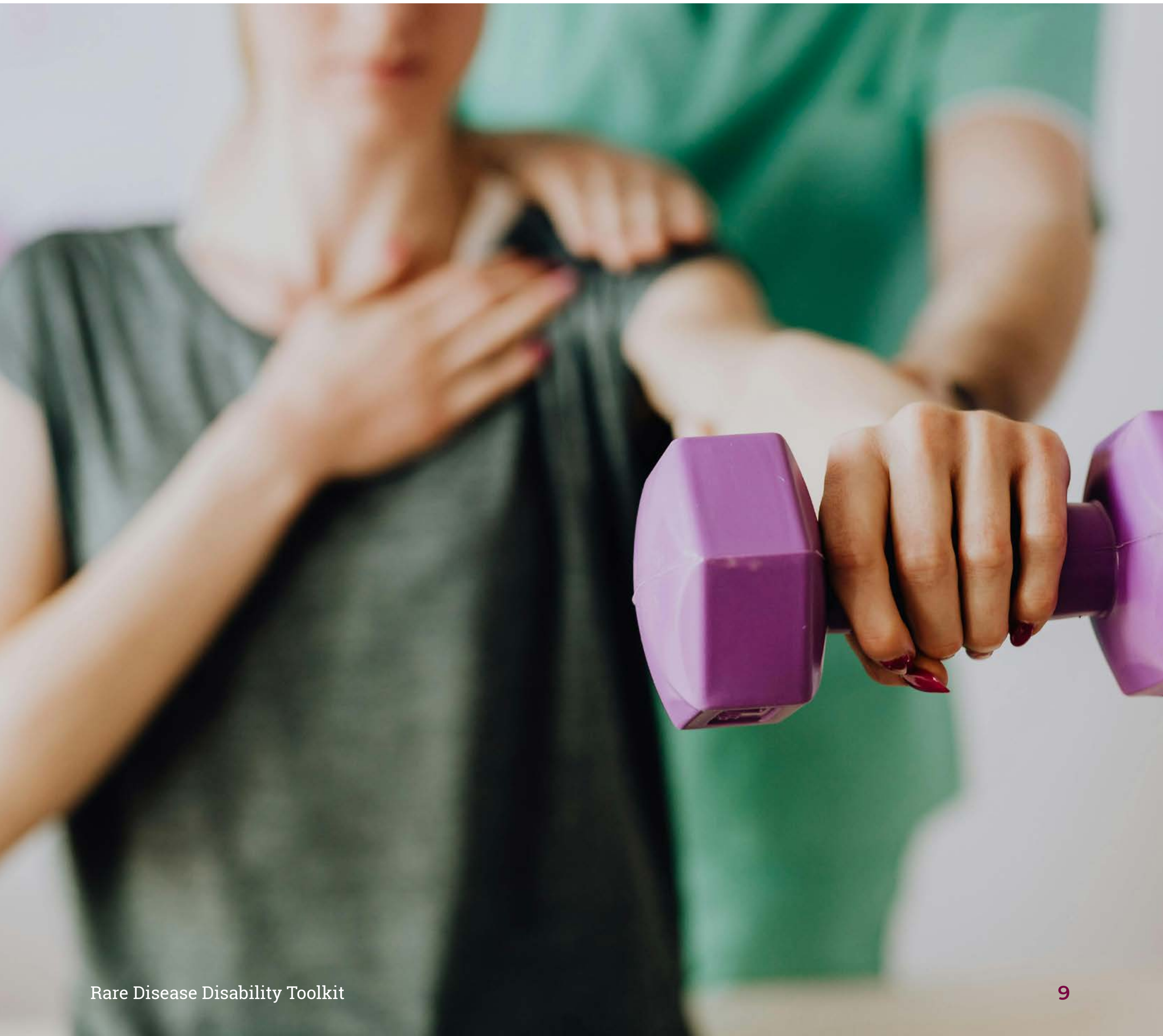
- Engage local **Aboriginal Community Controlled Organisations (ACCOs)**, and/or community connectors.
- Ensure culturally safe consent, sharing of results, and family-led goalsetting.
- Explore the Aboriginal and Torres Strait Islander people resources on the Rare Awareness Rare Education (RARE) Portal for practical links and services.

Assessments

To support applications, health professionals can complete one (1) or more of the assessments to describe how the person's impairment/s impact their functional capacity in one (1) or more areas.

Guidance on which assessments are recommended for different conditions or impairments, and which professionals should complete them, is listed on the NDIS' Types of Disability Evidence page. These **assessment/s** can be summarised in a **Functional Capacity Assessment (FCA) report**. However, even if these assessments are not completed, a health professional can still provide evidence of your permanent impairment/s and your functional capacity through a **NDIS Letter of Support.** (coming soon)

Note: For some disabilities, information about disability impacts may not be needed. These disabilities are included in List A - conditions which are likely to meet the disability requirements.



Reports and Letters of Support

The FCA or NDIS Letter of Support should be:

- **Recent** - Evidence must be contemporary, ideally less than twelve (12) months old, and reflect the current status of the person's condition and support needs.
- **Relevant** - Evidence must be provided by a health professional who is relevant to the primary impairment and ideally has been involved in the person's care for at least six (6) months.

  This does not mean that evidence will be excluded if the health professional hasn't been involved in the person's case for more than six (6) months, rather the NDIS may place less weight on it compared to other, stronger, evidence.
- **Original** - Evidence should be original, genuine and specific to the individual as opposed to generic about the condition/impairments.

The FCA or NDIS Letter of Support should include:

- Assessment of how the impairment/s **substantially** impacts one (1) or more of the following six (6) areas:
  - **Mobility/motor skills** (e.g. difficulty walking, fatigue, coordination issues)
  - **Communication** (e.g. speech delays, difficulty expressing needs)
  - **Social interaction** (e.g. isolation due to unpredictable symptoms)
  - **Learning** (e.g. cognitive fatigue, memory issues)
  - **Self-care** (e.g. needing help with hygiene or meals)
  - **Self-management** (e.g. difficulty planning, managing medications or finances).
- Evidence of how impairment/s impact social and/or economic participation (including work and/or study).
- Specific recommendations linked to NDIS goals (if relevant or known. E.g. independence, employment, community access).

  'Substantial' means the person usually requires disability-specific supports to undertake these tasks. For example, this may include a high level of support from others, specially prescribed assistive technology/equipment, or home modifications.

Who Can Provide Evidence?

Examples of typical health professionals who can provide evidence include (listed in alphabetical order):

- Audiologist
- Cardiologist
- General practitioner (GP)
- Geneticist
- Neurologist
- Occupational therapist
- Ophthalmologist
- Orthopaedic surgeon
- Paediatrician – Developmental or Specialist
- Paediatrician – General
- Physiotherapist
- Psychiatrist
- Psychologist
- Speech pathologist (Therapist).

It is important that evidence is provided by the health professional **most relevant** to your main disability or impairments. In complex cases, you may need reports from several health professionals, for example:

- A specialist or GP to help describe the diagnosis and establish permanency of the impairment, **and**
- An occupational therapist or physiotherapist to explain functional limitations.

Resources

- Use the **Checklist - NDIS Letter of Support – Health Professional** to assist in ensuring medical and allied health professional letters and reports meet the evidence requirements for the NDIS.
- Refer to the **Guidance – Writing a Letter of Support** (coming soon) for further explanation and guidance on how to write NDIS letters of support.

Diagnosis to Impairment

In January 2025, the NDIS shifted its focus when assessing new participants. The NDIS now also focuses on impairments, not only diagnosis, when assessing eligibility.

Eligibility for the NDIS and NDIS Supports is determined by the permanency and functional impact of impairments, rather than solely on diagnosis or condition. This closely aligns with the language and requirements in the NDIS Act 2013.

While a diagnosis is not required for eligibility, including it in documentation is helpful. It can assist the NDIS and other service providers in identifying associated impairments, understanding current and future disability impacts, what treatments are available, and determining appropriate support needs.

Impairment Definition

An impairment is defined by the NDIS as a loss of or damage to a person's body function, structure, and how they think.

The underlying disability impacts must be caused by an impairment, or multiple impairments. The impairments must affect the ability to work, study or take part in social/community life.

Many rare diseases and other conditions, syndromes and disorders will result in one (1) or more impairments. If multiple impairments exist, it is still necessary to identify them individually, while also describing how each impacts the individual.

Impairment Categories

The NDIS impairment categories are described as follows:

1. **Intellectual impairments** – how you speak and listen, read and write, solve problems, and process and remember information. An intellectual impairment may become apparent at an early age or during a child's early development.
2. **Cognitive impairments** – how you might think, learn new things, use judgement to make decisions, and pay attention. There are some similarities with intellectual impairments, but cognitive impairments may appear at a later stage in life or after a sudden event or injury.
3. **Neurological impairments** – how your body's nervous system may function. Neurological impairments can happen when there is a change in the function of the nervous system, such as in the brain or spinal cord. Damage to these parts of the body may affect the way the nervous system processes information.
4. **Sensory impairments** – how you see and hear. Sensory impairments usually relate to hearing or vision loss but may include all senses.
5. **Physical impairments** – the ability to move or control parts of your body. Physical impairments may affect your stamina, or how quickly your body gets tired.
6. **Impairments related to psychosocial disability** – this means you have reduced capacity for daily life activities and tasks due to your mental health.

Impairment Mapping and Information

The NDIS maps recognised rare diseases and other conditions, syndromes and disorders to impairment categories to help assess eligibility. This enables them to identify what impairment information to include in the NDIS **'Notice of Impairment'** issued to participants.

The Notice of Impairment includes the impairment/s for which the participant has met eligibility for NDIS access.

The NDIS uses the following lists to identify conditions and their associated impairments:

- List A: Conditions that are likely to meet the disability requirements – these conditions are considered to cause permanent impairment and disability resulting in substantially reduced functional capacity.
- List B: Conditions that are likely to result in a permanent impairment – these conditions may vary in the severity of the impairment so they will need to demonstrate additional evidence of their impairment/s and their functional impact.
- List D: Permanent impairment/Early intervention, under 7 years. No further assessment required – applies to children under 7 years old for conditions that are likely to result in permanent impairment/s. This may include Global Developmental Delay.

While some rare diseases, including recognised syndromes and disorders, are on these NDIS reference lists, having a diagnosis of a condition on the list is not required to gain access to the NDIS. Conditions that are not listed are considered on an individual basis, and eligibility is determined by the functional impact of the condition. Where available, referring to the relevant ICD (International Classification of Diseases) code can help support the evidence provided.

Individuals with an undiagnosed rare disease may still be considered eligible for NDIS access if there is strong evidence that the condition is **permanent** (or likely permanent) and causes **substantial** functional impairment in daily life.

Permanent Disability

To be eligible for the NDIS, your impairment, and not the cause or the diagnosis, must be permanent and unlikely to improve with treatment. Someone could have a permanent condition or rare disease, and it may not result in a permanent impairment.

Permanency considers if the impairment/s are lifelong and the impact of treatments on the impairment.

To meet the criteria for disability eligibility, you must show that:

- The impairment is enduring in nature and likely to persist across the person's lifetime.
- The impairment continues to **substantially** reduce functional capacity in daily life and impacts the ability to participate socially or in work/study.
- There are **no known, available, and appropriate evidence-based treatments** that would likely remedy the impairment, **and/or**
- All reasonable treatment options (including physical therapy, psychological support, diet, exercise, or other lifestyle interventions) have been explored or trialled, or discounted as they are not relevant, available, accessible or appropriate.

Permanency must be demonstrated and not just stated.

If no information is provided about the treatment options tried and the outcomes of these treatments, or the treatments that were discounted and the reasons why, the NDIS may consider that there is not enough evidence to determine that the condition is permanent.

Episodic conditions that have periods of regression or 'flare ups' may still be considered permanent where there is evidence of an overall substantial reduced functional capacity across time and a range of contexts.

Treatments

The NDIS definition of 'treatment' plays a critical role in determining whether a person's impairment is considered **permanent** for eligibility purposes. Applicants must show that all **known, available and appropriate evidence-based treatment options** have been explored and that the impairment is likely to remain regardless of further intervention.

The NDIS uses the term 'treatment' broadly. It considers treatment as any medical, clinical, or other intervention that could potentially remedy an impairment. Treatments include:

- Medications
- Therapies (e.g. physiotherapy, occupational therapy)
- Surgical procedures
- Lifestyle changes (e.g. diet, exercise)
- Rehabilitation programs.

What Treatments May Delay or Deny Eligibility?

Treatments that are medical, acute in nature, or need time to show effect on the impairment may delay or deny eligibility. For example:

- Recent surgery with expected recovery.
- Medication that may restore function.
- Therapy with a high likelihood of improvement.
- Acute injuries (e.g. fractures) expected to heal.

What Does the Law Say About Treatments?

To further explore how the NDIS looks at treatments, the Australian Federal Court[7] has established the following definitions:

- **Known:** Identified by an Australian medical practitioner as suitable for the impairment.
- **Appropriate:** Proven to be effective in remedying the impairment and suitable and safe for the individual.
- **Available:** Available in Australia and realistically accessible to the person, considering location, affordability, any genuine barriers and personal circumstances, including living arrangements.
- **Evidence-based:** There is proof the treatment is likely to be effective in remedying the impairment, not just symptom control.

The NDIS definitions are in Our Guidelines: Applying to the NDIS > Is there any medical treatment for your impairment?

What if a Treatment Is Not Appropriate for Me?

Even if treatments exist, the National Disability Insurance Agency (NDIA) considers whether they are suitable and accessible for the individual. This includes considering the person’s individual circumstances to access treatment and whether treatment is appropriate for them. Someone may have valid reasons for not pursuing a treatment, such as:

- It is invasive or carries risks given the individual’s situation.
- It is unaffordable.
- They don’t have the support needed to undergo or recover from it.

How Would a Treatment Remedy an Impairment?

For a treatment to be considered “likely to remedy the impairment” it is expected that, after completing the treatment, either the person will no longer have the impairment or the impairment will be significantly improved.

What if the Treatment Only Manages the Symptoms?

Even if a person is still undergoing treatment, the NDIS may consider the impairment permanent if it's clear the treatment won’t cure or significantly improve the condition. If the treatment only manages symptoms without remedying the impairment, the impairment may be considered permanent.

Treatment Versus Maintenance

What if More Treatment Is Recommended?

It is essential for health professionals to clearly describe the purpose of a treatment and what the outcomes are.

If a health professional recommends more clinical treatment (like surgery or changing medication) that **might improve or fix the condition**, the NDIS may decide the condition is **not yet permanent**, and the person may **not be eligible**.

If the treatment is clinical and **won't change the underlying condition**, the NDIS needs clear confirmation from the health professional that the condition is **permanent**, even though treatment is ongoing.

It's also common for people to keep undergoing **non-clinical treatments.** Not to fix the condition, but to **maintain function** and **prevent decline**.

If the condition is permanent and the NDIS is given evidence that the treatment is for maintenance, the NDIS is likely to still consider the person eligible.

To avoid confusion, this kind of ongoing treatment is often called:

- Functional maintenance therapy, or
- A therapeutic management plan.

Examples of non-clinical treatments include:

- Allied health therapy.
- Disability-related health supports.
- Nutritional supports.

Summary

Your healthcare professional must provide evidence that confirms that either:

- No **known, available or appropriate evidence-based** clinical, medical or other treatments exist that would likely remedy the impairment, **or**
- **All reasonable treatment options** have been explored or trialled and provide a summary of these, and the impairment remains, **and/or**
- If continuing treatment is recommended or required:
  - The intended purpose of the treatment.
  - The expected or intended outcomes.
  - Confirmation that **the treatment will not alter the permanence** of the impairment.

Rare Disease Disability Examples

These rare disease disability examples explore how individuals with rare disease disability may approach permanence and treatments. These examples have been developed with reference to the NDIS eligibility and medical conditions FAQ.

Neurological/Neurodevelopmental Impairments

To be eligible for the NDIS, a person must have a permanent neurological impairment that causes substantial functional limitations and that cannot be remedied through treatment, including surgery and/or medication. For example, if the medication assists in managing some of the symptoms of the condition but does not resolve the underlying impairment must be considered.

Some neurological conditions have symptoms that fluctuate or vary in intensity from day-to-day and week-to-week. However the neurological impairment may still be considered permanent if it continues to substantially reduce the person's functioning in one (1) or more areas of life over time.

Progressive and Degenerative Impairments

For rare diseases that are progressive/degenerative, it is important to clarify whether the person's **functional impairment is degenerative over time**, rather than solely noting that the underlying condition is progressive.

A degenerative, or progressive impairment, is likely to be considered permanent unless medical treatment can improve the impairment so that it no longer has significant impacts on day-to-day functioning.

For example, for a rare, genetic, inherited condition that progressively affects the nervous system and movement, it is important to show that the associated impairments will have progressive impacts. While the underlying condition itself is accepted to be genetic and degenerative, what matters for NDIS access is the impairment it causes. The impairments could include reduced mobility, difficulty with self-care, and impaired communication that worsens over time. If these impairments are unlikely to improve with medical treatment, they may be considered permanent under NDIS guidelines.

Episodic and Fluctuating Impairments

An impairment that is **episodic or fluctuates in intensity** can still be considered permanent if there is an **overall substantial impact** on the person's function in one (1) or more functional areas, and it is clinically established that they will be impacted across their lifetime. This means that an applicant may still have a permanent impairment, even if its impacts may change day-to-day or over time.

For example, individuals with rare conditions that affect cellular energy production may experience episodic impacts such as extreme fatigue, muscle weakness, seizures, or cognitive fog that fluctuate in intensity from day-to-day or week-to-week. Although the symptoms may not be constant, the impairments, which may include neurological, physical, sensory, and cognitive impairments, may be enduring and substantially affect the person's ability to function.

Children with Developmental Delay

Children aged under six (6) who have a suspected rare condition and a diagnosis of developmental delay may still meet NDIS eligibility where there is clear evidence of **substantial functional impacts** and **likely permanence**.

The NDIS criteria also includes:

- Whether the child requires ongoing, multidisciplinary support.
- Across home, community, and early learning settings.
- For a period of twelve (12) months or longer.

Undiagnosed Rare Conditions

For an undiagnosed rare disease, the NDIS will apply the eligibility criteria in the same way as any diagnosed condition. This includes whether:

- The impairment is permanent, even if the condition is not fully understood.
- The person has substantial functional limitations.
- Known, available and appropriate treatments have been explored and found ineffective or unavailable.
- The impairment is likely to persist, regardless of daily fluctuations.

Functional Capacity and Impacts

Functional capacity is the ability to carry out everyday tasks across different settings. When assessing the impact of an impairment, the NDIS looks at how independently you can complete these tasks, and where you need **disability-specific supports** to participate or complete the activities.

If you live with more than one (1) permanent impairment, all impairments should be considered together to understand their combined impact on your ability to function day-to-day.

You must show reduced function across whole activity areas, not just isolated tasks.

Disability-specific NDIS Supports may include:

1. **A high level of person-to-person support** such as physical assistance, supervision, prompting, or guidance—including visual tools to aid understanding.
2. **Assistive technology, equipment, or home modifications prescribed** by your doctor or allied health professionals to help you participate more fully in daily life.

Functional areas include:

- **Communicating** – how you speak, write, or use sign language and gestures, to express yourself compared to other people your age. This also includes how well you understand people, and how others understand you.
- **Socialising** – how you make and keep friends, or interact with the community, or how a young child plays with other children. This also includes looking at your behaviour, and how you cope with feelings and emotions in social situations.
- **Learning** – how you learn, understand and remember new things, and practise and use new skills.
- **Mobility, or moving around** – how easily you move around your home and community, and how you get in and out of bed or a chair. This also includes how you get out and about and use your arms or legs.
- **Self-care** – personal care, hygiene, grooming, eating and drinking, and health. This also includes how you get dressed, shower or bathe, eat or go to the toilet.
- **Self-management** – how you organise your life, plan, make decisions, and look after yourself. This may include day-to-day tasks at home, how you solve problems, or manage your money. This also includes your mental or cognitive ability to manage your life.

Lifelong NDIS Supports

If your impairment/s are lifelong, and you require ongoing disability supports, you may be eligible for **lifelong NDIS supports**.

The NDIA looks at the person's life circumstances, including:

1. Condition is best managed through the NDIS or other systems (e.g. health or aged care).
2. Person will need support to work, study, or participate socially over their lifetime.
3. Supports are NDIS Supports, as defined by the legislation.
4. NDIS Supports are likely to be required for the person's lifetime.

1. Is the condition best managed through the NDIS?

The NDIS is not responsible for all support needs, only those that are considered **NDIS Supports** and are best managed through the NDIS.

This matters for rare diseases because many people require intensive medical care alongside disability-related assistance. However, functional impairments, such as mobility limitations, communication challenges, swallowing difficulties, fatigue, cognitive changes, or behavioural impacts, may require disability supports that sit appropriately with the NDIS.

Some examples of supports best managed by other systems include:

- Childcare inclusion support.
- Education supports or reasonable adjustments in educational settings.
- Health supports or reasonable adjustments in healthcare settings.
- Housing support for people facing housing security challenges.

When seeking **NDIS Supports**, it is good to show how engaged with mainstream supports such as health, education, employment and other government and/or community funded programs and supports people are. This helps show the NDIS that you understand the broader support available and are only requesting the supports that fall within the NDIS' responsibility. Examples of helpful evidence include:

- Regular GP involvement including:
  - GP Comprehensive Health Assessment Plan (CHAP).
  - GP Mental Health and Wellbeing Plan.
  - Chronic Disease Management Plan.
- Parenting supports such as My Time Parent Group, playgroup or online parenting programs.
- Carer supports such as Carer Gateway programs or the Disability Gateway.
- Community groups (e.g. Men's Shed, Youth Group, Scouts/Girl Guides).
- Rare disease peer support groups, including online rare disease community forums.

2. The person will need ongoing support to work, study, or participate socially over their lifetime.

Rare diseases frequently impact education, employment and social inclusion due to their complexity and variability of impacts. Even when symptoms are episodic, the long-term support need may still be clear, for example, assistive technology, person-to-person support to help with planning and organisation, or communication aids.

3. The supports a person needs are considered “NDIS Supports” under legislation.

The NDIA must determine whether requested supports fit the definition of reasonable and necessary, are related to functional impairment, and not the responsibility of another system. Since 3 October 2024, laws changed how NDIS funding can be used, including the introduction of a clear definition of “NDIS Supports”.

Participants can now only use their NDIS funds for items and services that are officially recognised as NDIS Supports.

The NDIA has published support lists that show:

- What is a NDIS support.
- What is not a NDIS support.
- What may be allowed as a replacement support in special cases

4. Are lifelong NDIS Supports required?

Even if a rare disease has episodic or fluctuating presentation, and support needs go up and down over time, the NDIS may still consider that a person will need NDIS Supports for their lifetime.

This is particularly relevant for rare diseases where:

- Progression is expected but timing is uncertain.
- Symptoms fluctuate but functional impairment remains significant.
- Risk factors (e.g., respiratory decline, seizures, metabolic instability) require ongoing safeguards.

Many rare diseases on **List A** or **List D** meet the disability requirements and require lifelong NDIS Supports. Other rare diseases and conditions may require additional detailed evidence to demonstrate lifelong-term impairment and functional impacts.

Writing Risk Summaries for NDIS Access or Support

Medical and allied health practitioners should describe the potential risks to the participant's wellbeing, safety, and social/economic participation if access to requested NDIS Supports are declined.

What to Include in a Risk Summary

1. Risk Identification

- Clearly outline what could happen without NDIS support.
- Identify if disability-related health supports are needed to help manage diagnosed conditions such as dysphagia and/or mealtime management, including enteral feeding, wound care, continence support and complex bowel care. There can be significant risk of harm if these supports are not accessed.
- Include risks such as:
    - Health deterioration, including documented rapid progression
    - Significant loss of skills
    - Carer burden and/or burnout
    - Social isolation
    - Inability to attend school/work
    - Safety concerns at home
    - Functional decline and increased support needs over time
    - Potentially preventable disability-related hospital admission.
- If applicable, explain how early investment may reduce long-term costs.

2. Impact Assessment

- Describe the **severity** and **likelihood** of each risk.
- Use real-life examples or past incidents to illustrate consequences.

3. Safeguarding Gaps

- Explain which NDIS Supports are essential, and why they are the responsibility of the NDIS, and cannot be replaced by other systems (e.g. health, education, housing).

4. Support Network Input

- Include statements from carers, clinicians, or support coordinators.
- Highlight previous attempts to access alternative supports and their limitations.

5. Priority Pathway Consideration

- Indicate how the participant may meet the criteria for a **priority pathway** application.

Priority Pathways

An individual may qualify for a NDIS priority pathway with faster eligibility decisions if urgent needs or significant risks are identified. These priority eligibility assessment pathways are described in the NDIS Operational Guideline – Applying to the NDIS.

Note: To meet access to the NDIS, you must still meet all the access evidence and eligibility criteria described in this guide.

If you're in one (1) of the following situations, the NDIS will aim to decide if you're eligible within **two (2) to five (5) business days:**

- Child younger than seven (7) years with a hearing impairment, either:
    - Identified as Hearing Australia or Early Childhood Partner Priority.
    - Identified as newly diagnosed.
- A child is identified as having a developmental delay and is turning six (6) years old within thirty (30) days of a valid NDIS application.
- Immediate risk to self, others, or community where appropriate disability or informal supports are not in place.
- Unexpected, significant deterioration of disability-related functional capacity where appropriate disability or informal supports are not in place.
- Rapid deterioration in functional capacity of a person with one (1) of the following permanent disabilities:
    - Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig's Disease)
    - Brain cancer
    - Motor Neurone Disease (MND)
    - Progressive Bulbar Palsy (PBP)
    - Primary Lateral Sclerosis (PLS)
    - Progressive Muscular Atrophy (PMA).
- A terminal illness and disability.
- Imminent risk (within 1–14 days) of breakdown of either:
    - Accommodation – risk of homelessness.
    - Caring arrangements, including informal supports, due to death, serious illness or injury of informal supports, or significant and unexpected deterioration of disability-related functional capacity.
- Appropriate disability supports are not in place, and an individual is re-entering the community after a long-term residence or hospital stay (specific release date not required). This may apply to:
    - A person with a newly acquired, significant disability, such as spinal cord injury, being discharged from hospital.
    - A younger person living in residential aged care.
    - A person being discharged from an inpatient mental health facility.
    - A person due to be released from a correctional facility.

Glossary of Key Terms

Access

The process of applying to become a participant in the NDIS. Access requires meeting specific eligibility criteria, including age, residency, and disability and/or early intervention requirements.

Diagnosis

The process of identifying a condition or issue causing the person’s symptoms or problems. While not required for NDIS eligibility, a diagnosis can help identify associated impairments, understand current and future disability impacts, and determine appropriate support needs.

Disability Requirements

Includes having a permanent impairment that substantially reduces functional capacity and requires disability-specific supports, and likely lifelong need for NDIS Supports.

Early Intervention

Providing support to a person, either a child or an adult, as early as possible to reduce the impacts of disability or developmental delay and build skills and independence.

Eligibility

To be eligible for the NDIS, a person must meet age, residency, and either disability or early intervention criteria.

Functional Capacity

The ability to carry out everyday tasks across different settings. The NDIS assesses how independently a person can complete tasks and where disability-specific supports are needed.

Functional Capacity Assessment

An assessment completed by a health professional that records functional capacity across the six (6) functional areas. It also contains information about how the person’s impairment/s impact daily life, and social and/or economic (work/study) participation.

Health Professional

A qualified practitioner who can provide evidence for NDIS access. This includes medical professionals such as GPs and medical specialists, and allied health professionals such as occupational therapists, physiotherapists, and speech pathologists.

Impairment

Defined by the NDIS as a loss of or damage to body function, structure, or cognitive ability.

Mainstream Supports

Supports provided by systems outside the NDIS, such as health, education, housing, and employment services.

NDIS Supports

Supports the NDIS funds that relate to a participant's disability. NDIS Supports are the services, items and equipment that can be funded by the NDIS.

Permanency

A lifelong impairment that is unlikely to improve with known, available, and appropriate treatments. Permanency must be demonstrated through evidence, not just stated.

Recent

Evidence must be contemporary, ideally less than twelve (12) months old, and reflect the current status of the person's condition and support needs.

Relevant

Evidence must be provided by a health professional who is relevant to the primary impairment and has ideally been involved in the person's care for at least six (6) months.

Remedy

To eliminate, or significantly improve, an impairment through treatment. If treatment only manages symptoms without curing the impairment, the impairment may still be considered permanent.

Substantial Impact

A substantial impact is where a person's permanent or likely permanent impairment causes significant difficulty carrying out everyday activities. This means the person is **unable to participate effectively or fully** in one (1) or more key areas of daily functioning (i.e. communication, social interaction, learning, mobility, self care, or self management) without **specialised supports or assistive technology**.

This level of difficulty must be present on most days and reflect a **significant limitation or restriction**, rather than a minor or occasional challenge.

The NDIA also reviews whether a person is impacted in their ability to work/study or socially participate, but the level of impact is not necessary to note.

Social Participation

The ability to engage in community life, make and keep friends, and interact socially. Impairments that limit social participation are considered in NDIS eligibility assessments.

Treatment

Any medical, clinical, or therapeutic intervention that could potentially remedy an impairment. Includes medications, therapies, surgeries, and lifestyle changes. The NDIS considers whether treatments are known, available, appropriate, and effective.

Resources

National Disability Insurance Scheme: Am I eligible?

National Disability Insurance Scheme: Eligibility and medical conditions FAQ

National Disability Insurance Scheme: NDIS Operational Guideline – Applying to the NDIS

National Disability Insurance Scheme: Operational Guideline – Applying to the NDIS; List A: Conditions that are likely to meet the disability requirements

National Disability Insurance Scheme: Operational Guideline – Applying to the NDIS; List B: Conditions that are likely to result in a permanent impairment

National Disability Insurance Scheme: Operational Guideline – Applying to the NDIS List D: Permanent impairment/Early intervention under 7 years

National Disability Insurance Scheme: Participant safeguarding policy

National Disability Insurance Scheme: Providing evidence of your disability

National Disability Insurance Scheme: Supports funded by the NDIS

National Disability Insurance Scheme: Types of disability evidence

National Disability Insurance Scheme: Operational Guideline – Applying to the NDIS; What are the categories of impairments?

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