Guidance – Writing a Letter of Support for Rare Disease Disability

For Health Professionals

Introduction

This guidance document is part of the nationally codesigned Rare Disease Disability Toolkit (the Toolkit). It is intended to support health professionals to prepare clear, relevant evidence for individuals living with rare disease disability who are applying to the National Disability Insurance Scheme (NDIS) for either:

- NDIS Access
- Ongoing NDIS eligibility or
- Assessment of NDIS Supports.

This resource is a companion to Rare Voices Australia's (RVA) **Guide – NDIS and Rare Disease Disability – Part 1: Access and Eligibility**, which explains key eligibility concepts, legislative context, and frequently used NDIS terminology.

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

This guidance is intended to function as a **clinical reasoning aid**. It provides practical prompts and examples to help clinicians explain:

- The presence of impairment.
- The functional impact of impairment in daily life.
- The permanency of impairment.
- Why ongoing disability specific supports are required.

This guidance is **not a template**. It does not prescribe wording or structure, and examples should **not be used verbatim**. Effective letters remain **individualised, clinically accurate**, and **grounded in professional judgement**, while aligning with the National Disability Insurance Agency (NDIA) decision making criteria described in the **NDIS Guidelines**.

Clinician Tip: Framing the Conversation (Why We Use This Language)
Many clinicians and families prefer strengths-based and person-centred language. However, the NDIA's access and funding decisions are based on evidence of **impairment** and its **functional impact** on daily life. Letters may need to describe what the person **cannot do** without support, and what happens when supports are reduced or absent.

Some of the wording may feel uncomfortable, and the process of describing impacts and support needs can be stressful for individuals and families/ caregivers. It's important to provide support and pathways for mental health support. See RVA's Digital Mental Health factsheet, which has been developed for Australians living with a rare disease, including families and caregivers.

How to Use This Guidance

1. Review the Guide – NDIS and Rare Disease Disability – Part 1: Access and Eligibility to understand eligibility concepts and legislative context.
2. **Draft a letter** of evidence based on your clinical assessment and professional judgement.
3. Use this guidance as a **prompting tool** to:
    - Check whether key NDIS concepts (impairment, function, permanency, treatment) have been adequately addressed.
    - Strengthen clarity and specificity in describing functional impact.
4. Use the Checklist – NDIS Letter of Support for Health Professionals as a final quality check.

This guidance is not intended to be read or applied sequentially. Health professionals may refer to relevant sections as needed.

Clinician Expertise and Relationship to the Person

NDIA decision makers must be confident that the clinical evidence provided is **relevant, informed and based on sufficient longitudinal knowledge** of the person.

Health professional letters may assist decision making where they clearly establish:

- Their professional role and scope of practice.
- The length of time they have been involved in the individual's care (ideally > 6 months).
- The nature of their involvement (e.g. regular consultations, specialist assessments, ongoing therapy).
- The relevance of their expertise to the individual's primary impairment(s), including diagnostic or therapeutic responsibilities (i.e. why they are the most appropriate person to be writing this letter).

The purpose of this information is to contextualise **why the clinical opinion can be relied upon** in determining impairment, functional impact, and permanency.

Important: Letters must be signed by an Australian Health Practitioner Regulation Agency (AHPRA) registered practitioner.

Where a letter relates to a medical specialty, it must be signed by the relevant AHPRA registered specialist.

Understanding the Person

NDIA assessments are individualised. Decision-makers consider the clinical information within the broader context of **how the person functions within their real world.**

Providing a brief description of the individual beyond their diagnosis can assist, and may include their strengths and interests, aspirations and goals, and how the person typically participates in family, education, work, or community life.

Illustrative Framing

"Outside of clinical settings, [person] enjoys [interests]. However, their participation is significantly restricted by..."

Social and Environmental Context

The NDIA considers the **interaction between impairment and environment**, including:

- Support availability
- Family and carer capacity
- Social, cultural, financial, and environmental factors.

It may be relevant to describe if environmental demands compound disability impacts, or where there are concerns about family/caregiver capacity and sustainability to provide support.

Considerations may include:

- Capacity to self-manage a rare disease condition and its associated impairments.
- Housing security, financial challenges, capacity issues, child safety or justice issues.
- Connections with mainstream and community services and support including, for example:
  - Early childhood support
  - School/Education
  - Employment (including voluntary and paid work)
  - Healthcare
  - Community – such as clubs, groups, sports, churches etc.

Illustrative Framing

"The functional impact of this impairment is amplified by environmental factors including…"

"Without structured supports, the reliance on informal carers is unsustainable."

Describing Diagnosis and Medical Information

NDIS eligibility is based on the presence of impairment that meets its legislative definitions, **not the diagnosis itself**. A confirmed diagnosis is **not required**; however, diagnostic information may assist in understanding the nature and expected course of impairment. **Relevant medical history** should also be outlined, including co-morbidities or other factors that may contribute to, exacerbate, or compound the overall impact of the impairment(s).

Health professionals are encouraged to describe the **individual's lived experience** of the rare disease and how the condition currently affects them, including how disability impacts may change over time, even where future progression is uncertain.

Where a Diagnosis Is Known

Where a diagnosis is known, it is useful to provide a plain-English description of the key features of the condition and associated impairments, the expected progression and/or variability, and severity of the impacts.

To ensure accurate data capture, it is important to use relevant diagnostic codes, where available.

Consider including an Online Mendelian Inheritance in Man (OMIM) reference, Orphanet code, or, if available, a Diagnostic and Statistical Manual of Mental Disorders (DSM) or International Classification of Diseases code.

Where a Diagnosis Is Not Yet Known

Where a diagnosis is not yet known or confirmed, health professionals should endeavour to describe the:

- Individual's **presenting symptoms and pattern of impairments**.
- **Likely course** of the condition.
- **Investigations undertaken, underway, or being considered**. This may include details of genetic testing or other diagnostic assessments.

Illustrative Framing

"Although a definitive diagnosis has not yet been confirmed, [person] presents with a consistent pattern of impairments that have persisted over time."

"This condition is rare, and current evidence indicates a variable but enduring course."

Describing Impairment Information

The NDIA assesses disability based on categories of impairment, rather than medical conditions.

Health professionals are encouraged to use the **NDIS categories of impairment**, supported with appropriate evidence to record primary and other relevant impairments:

- **Primary impairment:** Focus on the impairment with the greatest impact.
- **Record other relevant impairments** that contribute to disability.

Many rare disease conditions may have **multiple impairments**, which may coexist across several areas and compound overall disability.

If listing symptoms, it is useful to link these and other clinical findings to the relevant NDIS impairment categories.

The NDIS categories of impairments are:

- **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.
- **Cognitive impairments** – how you think, learn new things, use judgement to make decisions, and pay attention. There are some similarities with intellectual impairments, but cognitive impairments typically appear at a later stage in life or after a sudden event or injury.
- **Neurological impairments** – how your body's nervous system functions. 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.
- **Sensory impairments** – how you see and hear. Sensory impairments usually relate to hearing or vision loss but may include all senses.
- **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.
- **Impairments from psychosocial disability** - reduced capacity to do daily life activities and tasks due to your mental health.

Illustrative Framing

"The primary impairment is neurological in nature, with the following symptoms... It also results in secondary impacts across physical and cognitive impairment categories as evidenced by..."

"These impairments coexist and compound overall functional limitation."

Describing Functional Capacity and Impact on Daily Life

This is the **most critical component of NDIS evidence.**

NDIA decisions are based on the impact of a condition on a person's function, including what they can and cannot do due to their impairment. It is not based on a diagnosis or description of symptoms alone.

Health professionals are encouraged to:

- Describe **functional impact across one or more NDIS functional area**.
- Use **specific, observable examples** rather than generalised statements.
- Outline what the person cannot do **without support**, including human support, assistive technology, or modifications.
- Include the frequency, duration, and variability of the impact/support needs (e.g., most days, during exacerbations, overnight).
- Note impacts on **education, employment, and social participation** where relevant.

Strengths and goals can still be acknowledged elsewhere in letters. However, NDIA decision-making relies on clear descriptions of functional impact and required supports.

Where helpful, clinicians may present information in a table linking impairment, functional impact, and support needs. This is optional and not required. An example is provided on page 8.

The NDIS functional areas are:

- **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 (if older than 6) –** 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.

Illustrative Framing

"As a result of this impairment, [person] is unable to do the following...and requires the following support [examples of support]."

"These limitations significantly restrict [person's] ability to participate in education/work/community in the following ways..."

Impairment	Functional Area	Functional Impact	Support Required
Intellectual **Neurological** **Physical**	**Self-care**	Cannot toilet, shower, dress or sleep safely; unsafe nocturnal behaviour due to seizures	Complete person-to-person physical support for self-care; shower chair and mobiliity walker for in home use for safe mobilising and falls prevention; assistive technology for seizure monitoring; **1:1 awake overnight support** due to behaviours of concern during 10pm and 6am. Continence aids.

Explaining Permanency of Impairment

NDIS eligibility requires evidence that impairment is **permanent or likely to be permanent**. This means the impairment/s are enduring across the person's lifetime and unlikely to improve with known, appropriate treatments.

Permanency must be **demonstrated through clinical reasoning**, not simply stated. Health professionals may **explain permanency** with reference to:

- Genetic or neurodevelopmental origin.
- Natural history of the condition.
- Progressive, degenerative, episodic or fluctuating patterns.
- Lack of available or effective curative treatments.

Note if any of the following are applicable:

1. Neurological/Neurodevelopmental impairments that are lifelong.
2. Progressive/Degenerative impairments that will worsen over time.
3. Episodic or fluctuating nature of the impairments and their overall impact over time.
4. Relating to children with developmental delay.
5. Are likely to be impairments caused by an undiagnosed rare disease.

If there is **no clinical justification** for why the condition is likely to be permanent, and there is no information provided on the **treatment options explored, trialled or even discounted**, the NDIS will likely consider that permanency cannot yet be determined.

Illustrative Framing

"Based on current clinical evidence and [medical testing/assessments], this impairment is expected to persist across the person's lifetime."

"Although symptoms may fluctuate, and may be managed to some degree with medications, the underlying impairment is enduring and permanent."

Treatment History and Clinical Rationale

The NDIA considers whether **impairment/s could be remedied** through treatment.

The NDIS definition of "treatment" is central to determining whether a person's impairment is considered permanent for eligibility purposes. The NDIS uses the term "treatment" broadly. It considers treatment as any medical, clinical, or other intervention that could potentially remedy an impairment. This includes:

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

Strong evidence explains treatments within the following contexts:

- **Medical treatments:** Include medications, surgeries, studies, assessments or interventions.
- **Therapies:** Include the type, frequency, duration of therapies and/or lifestyle changes and the focus area/s.
- **Outcomes:** Describe the outcomes of treatments or therapies, including any limitations.
- **Clinical rationale:** If certain treatments were discontinued or not pursued.

Health professionals are encouraged to clearly distinguish between **treatment**, **management**, and **support**.

Illustrative Framing

"All reasonable treatment options (including physical therapy, psychological support, diet, exercise, or other lifestyle interventions) have been explored or trialled and the impairments remain permanent."

"Interventions have supported symptom management but have not altered the underlying functional limitation."

"They have participated in the following therapies:

E.g. Occupational Therapy: Commenced [Month, Year], weekly sessions (45 mins), focused on fine motor skills, sensory regulation, and self-care. Outcomes have included improved ability to participate in personal care tasks. Despite these efforts, the impairments remain and are permanent."

"There are no known, available, and appropriate evidence-based treatments that would likely remedy the impairment."

"The following treatment options have been discounted as they are not relevant, available, accessible or appropriate to the individual in consideration of [risks, relevance to the condition and available evidence] and/or [individual's suitability for treatment options, including their preferences]."

Considering Future Treatment and Management

The NDIA distinguishes between ongoing disability support, the need for medical treatments, and the management of health symptoms.

It may be helpful to describe:

- Any **recommended** or anticipated future treatment options.
- The expected **outcomes** of these treatments.
- Whether the proposed treatment is intended to **manage symptoms or is likely to remedy the impairment** so that it no longer has a substantial impact on the person's day-to-day functioning.

Illustrative Framing

"The impairment symptoms may fluctuate, but treatment will not eliminate the impairment due to being a genetic neurodevelopmental condition."

Documenting ongoing health and disability related management plans may assist in clarifying the ongoing need for disability specific support.

These may include, but are not limited to (in alphabetical order):

- Continence and Complex Bowel Management Plan
- Diabetes Management Plan
- Dysphagia/Mealtime Management Plan
- Manual Handling Plan
- Positive Behaviour Support Plan
- Seizure/Epilepsy Management Plan
- Wound Care and Pressure Sore Management.

Considering Risks in the Absence of Support

The NDIA considers risk, sustainability and value for money.

It can be useful to describe any short-term and long-term risks to the individual (and their family, goals, and social/environmental context) if NDIS Access, ongoing NDIS eligibility or recommended NDIS Supports are not approved.

Consider the likelihood of the following:

- The need for increased NDIS Supports over time (including the type of support).
- Functional decline or deterioration in health.
- Inability to attend school/work or maintain community connection.
- Increased carer stress or burnout, including breakdown of informal support networks.
- Potentially preventable hospital admission/s.
- Any disability-related health supports needed, including dysphagia management, enteral feeding, wound care, continence support, and complex bowel care. There may be a significant risk of harm if these supports are not accessed.
- If relevant, it may be useful to include if and how investment in disability supports now can represent better value-for-money over the longer term.

Illustrative Framing

"Without adequate supports, there is a significant risk of..."

"The absence of timely support is likely to result in avoidable health deterioration, potentially preventable hospital admission, and increased disability support costs over time."

Recommended NDIS Supports (Optional)

If recommending specific NDIS Supports for individuals living with rare disease disability and their families/caregivers, the following list is provided as a guide only and is not exhaustive. Access the full list of **NDIS Supports**.

It is necessary for recommendations to be supported by appropriate and relevant evidence and linked to disability-related impacts from the impairments.

☐ Daily Living:

- ☐ Personal care support
- ☐ Assistance with daily living
- ☐ Overnight support
- ☐ Social and community access
- ☐ Nursing support

☐ Disability-Related Health Supports (DRHS):

NDIS funded nursing and therapeutic supports for people who need help managing their health conditions due to their disability. The NDIA funds eight main DRHS areas:

- ☐ Complex Continence/Bowel Management
- ☐ Diabetes Management
- ☐ Dysphagia
- ☐ Epilepsy
- ☐ Nutrition
- ☐ Podiatry and Foot Care
- ☐ Wound and Pressure Care
- ☐ Respiratory Supports

☐ Consumables:

- ☐ Continence aids (disposable and washable)
- ☐ Specialised feeding support (including thickeners)
- ☐ Specialised complex bowel care
- ☐ Low-cost assistive technology

☐ Therapy:

- ☐ Behaviour Practitioner
- ☐ Dietitian
- ☐ Exercise Physiology
- ☐ Music Therapy
- ☐ Occupational Therapy
- ☐ Orthotist
- ☐ Physiotherapy
- ☐ Podiatrist
- ☐ Psychologist
- ☐ Speech Therapy/Pathology
- ☐ Other

☐ Equipment:

- ☐ Assistive technology
- ☐ Assistance animal
- ☐ Mobility aids
- ☐ Communication aids/devices and applications
- ☐ Orthotics and customised/ medical grade footwear
- ☐ Grab rails
- ☐ Shower chair etc.

☐ Respite:

Regular respite to sustain informal support network due to:

- ☐ High intensity support needs
- ☐ Disability-related support needs
- ☐ Intensive behaviour support
- ☐ Carer responsibilities for others, including with a disability
- ☐ Carer illness/burnout, hyper-vigilance for risk
- ☐ Lack of accessible support in the area

☐ Support Coordination:

Support coordination for service connection, parental capacity building, optimising mainstream supports and safeguarding due to identified risk factors.

Glossary of 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.

Guidance – Writing a Letter of Support for Rare Disease Disability

For Health Professionals

This resource is part of the nationally codesigned Rare Disease Disability Toolkit and is accurate at the time of publishing (July 2026). **For more information, see the *NDIS and Rare Disease Disability – Part 1: Access and Eligibility* guide**. The information provided does not necessarily represent the views of Rare Voices Australia (RVA) or imply endorsement. RVA is not liable for any loss, damage, or consequences arising from the use or misuse of this resource.