



# Submission to the NDIS Review

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# Contact

**Jo-Anne Hewitt**

Chief Executive Officer

**Achieve Australia**

0429 771 716

[jhewitt@achieveaustralia.org.au](mailto:jhewitt@achieveaustralia.org.au)

# Acknowledgement

Achieve Australia acknowledges the Traditional Custodians of the lands on which we operate and pay our respects to Elders, past, present and emerging. We recognise the enduring relationship Aboriginal and/or Torres Strait Islander peoples have with Country and that sovereignty was never ceded.

Achieve is also proud to support the Uluru Statement from the Heart. We accept the invitation from the Uluru Statement to all Australians to support constitutional and structural reform so Aboriginal and Torres Strait Islander people can take their rightful place in our nation including being a voice to our Federal Parliament.

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## Foreword

Achieve Australia is grateful for the opportunity to provide our submission to the National Disability Insurance Scheme (NDIS) Review.

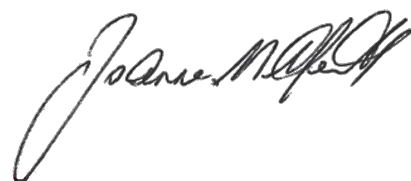
Achieve is passionate about helping people with disability to build extraordinary lives. We are widely recognised as a leader in supporting people with complex disabilities and re-imagining community living for people with disability.

Achieve shares the Independent Review Panel's vision of the NDIS for maximising the autonomy of people with the most complex disabilities, based on a social model of support.

Our principles of Living inclusion, Elevating voices, Engaging practice, Growing capacity and Valuing resources have guided our recommendations for a much needed reset to the NDIS.

The NDIS Review represents a once in a generation opportunity to recommend the scheme returns to its original premise.

I encourage the Panel to think boldly and recommend an NDIS that works for people with complex needs.



**Jo-Anne Hewitt**  
Chief Executive Officer  
**Achieve Australia**



# 1. Introduction

The NDIS has transformed the lives of people with disability who have received the right support.

During the inception and growth of the NDIS, Achieve Australia has helped people with disabilities to significantly improve their independence and quality of life by:

- moving out of institutions into the community, often for the first time
- tailoring services as their needs changed
- avoiding lengthy hospital stays through preventive health planning and respite.

However, current policy settings and funding models do not support people with complex and acute needs to maximise their choice and control.

The default approach is a disjointed, multi-service, highly medicalised model that limits people's independence and quality of life.

As a result, people with complex and acute needs are currently:

- suffering serious preventable health issues
- unnecessarily hospitalised
- living in accommodation that does not meet their needs
- dying prematurely.

This means that people with disability are missing opportunities to live independently and well: not because governments do not know how, but because people with disability do not have access to the right supports and services.

**People with disability need a social model of care that is based on the NDIS' original premise: to support people with the most complex disabilities to live their best life by providing access to lifelong care.**

## 2. People with Complex & Acute Needs

A person is considered to have complex and acute support needs when intellectual disability occurs with other issues including:

- mental illness
- complex health conditions and communication needs
- behaviours that may be a harm to themselves or others
- alcohol or substance misuse
- homelessness or involvement with child protection or criminal justice systems.

These support needs may be:

- simultaneous, intense, multiple and/or chronic
- episodic with periods of significant fluctuation or deterioration.

There may be complexity through gender or ethnicity and being an Aboriginal or Torres Strait Islander person (Dowse et al 2019). Complexity can also arise from people's life circumstances, past trauma, institutionalisation and social isolation.

Approximately 450,000 people have intellectual disability in Australia (Australian Government Department of Health 2023). Compared with the general population, people with intellectual disability experience:

- more than twice the rate of avoidable deaths
- twice the rate of emergency department and hospital admissions
- substantially higher rates of physical and mental health conditions
- significantly lower rates of preventative healthcare.

People with intellectual disability face stark health inequalities leading to at least 38 per cent of people dying from potentially avoidable causes and dying 27 years earlier than the general population (Trollor et al 2019).

## Support Requirements

Effective service delivery for people with complex and acute needs requires coordinated expertise from services and professions including:

- disability support providers
- primary, allied and acute health services
- behaviour support and mental health practitioners
- community and employment services.

## Current Issues

Achieve Australia supports around 520 people with:

- a primary intellectual disability
- physical and psychiatric disability
- an acquired disability.

These attributes are based on an impairment of functioning approach and are associative functional descriptors, not definitions of disability.

### **The majority of our clients have complex and acute support needs.**

- 98% require active overnight support
- 87% require medication administration
- 31% require seizure management
- 68% require communication assistance
- 73% require meal assistance
- 57% require behaviour support
- 40% require wheelchair access
- 32% require hoists
- 32% require dysphasia management
- 10% require PEG feeding.

This complexity is reflected in:

- the diversity of services and support required to maximise each person's choice, control and quality of life
- our highly skilled workforce and commitment to learning and development
- our rigorous quality and safety frameworks, clinical governance and risk management
- a higher client to FTE ratio (1.55 compared to the NDIS average of 1.81).



Person-centred and individualised support for people with complex support needs is the only way to ensure full inclusion in their communities.

Effective services that help people with complex and acute needs to maximise their quality of life are based on:

- responsive and adaptive supports
- collaborative planning across systems and services
- integrated systems and services overseen by an appropriately qualified coordinating organisation.

## Recommendations

- The NDIA should:
  - adopt a consistent evidence-informed definition of complex and acute needs
  - commit to targeted early and ongoing intervention to improve participants' quality of life
  - minimise the impact of planning and review processes on participants
  - establish an independent group to provide advice on the implementation of NDIS Review recommendations with representation from:
    - + people with intellectual disability, their families and carers
    - + disability service providers
    - + universities
    - + accreditation and registration bodies
    - + federal, state and territory governments.
- NDIS participants with complex and acute needs should have access to a 'whole of life' case management model, rather than annual or multi-year plans.
  - The NDIA should fund these participants' supports based on expert advice and clinical assessments of their current needs, which may fluctuate significantly without warning.
  - Appropriately qualified service providers should be involved in case management discussions to ensure that funding meets participants' current support needs, based on the NDIS Practice Standards.

## Impact

- A 'whole of life' case management model supports participants to live a dignified life, with meaningful relationships and positive community connections.
- This approach would:
  - improve participants' health and quality of life outcomes
  - build participants' capacity and protect their autonomy in a trauma-informed manner
  - provide clear duty of care arrangements across multiple service providers.

## 3. Mainstream Health Services & the NDIS

### NDIS Review Questions

- What services and supports should be available to people with disability outside the NDIS and who should provide them?
- How can governments work better to deliver a joined up system of inclusion and support for all Australians with disabilities (within and outside the NDIS)?

### Current Issues

- People with complex and acute needs require specialist support to monitor their health and care needs, assist with making decisions and accessing mainstream health services.
- This complexity is reflected in:
  - people’s histories of trauma, institutionalisation, chronic health conditions, behavioural and communication issues
  - the range of support required to maximise participants’ quality of life and independence
  - the highly skilled workforce, rigorous quality and safety frameworks, clinical governance, commitment to learning and development required to provide quality services.
- People with disability have significantly higher rates of (AIHW 2022):
  - emergency department and hospital admissions
  - obesity, hypertension and poor nutrition
  - psychological stress
  - chronic disease such as diabetes, stroke, osteoporosis and arthritis
  - deteriorating and fluctuating health episodes.
- People with complex and acute needs require additional care and support to address health issues that are caused or exacerbated by their disability.
  - This includes High Intensity Personal Activities (HIPA) such as Complex Bowel Care, Enteral Feeding and Management, Tracheostomy Care, Urinary Catheter Management, Complex Wound Management, Seizure Management and Dysphagia Management.

- They also require a greater level of nursing in long term care as their formal care requirements increase as they get older.
- The NDIA does not fund support required for participants to access mainstream health services.
  - People with complex and acute needs may require specialist support to explain their needs and access health services.
  - The NDIA argues that ‘health concerns’ are not connected to a participant’s disability and should be funded through mainstream services.
  - However, NDIS participants cannot access preventative and ongoing health services on the same basis as people without a disability.
- This results in:
  - participants missing out on preventative and timely health care
  - delayed or additional medical treatment
  - service providers subsidising participants’ access to health services, including lengthy respite.

## Recommendations

- NDIS participants should have a registered health care plan that:
  - sets out their needs
  - provides support to manage potential risks
  - provides safe and effective supports to achieve their goals.
- The NDIA should elevate health care planning for people with complex needs to the same status as behaviour support planning.
- The NDIA should adopt a holistic approach for supporting people with complex and acute needs including adopting:
  - recommendations for support and care from health professionals and appropriately qualified service providers
  - trauma-informed person-centred practice, based on inclusion, respect and choice
  - a transparent and inclusive approach to planning and reviewing decisions.

- The NDIA should provide funding to:
  - support participants' whole of life continuity of care based on active health care planning
  - build participants' capacity to access mainstream services and make timely decisions about their healthcare including chronic health assessments and preventive medical plans
  - for participants to access health services in their homes with appropriate support
  - ensure a person's health status is regularly reviewed by an appropriately qualified health practitioner
  - support episodes of acute care, based on clinical advice
  - support medical interventions that are particularly challenging for people with complex and acute needs e.g. catheters
  - support hospital attendance and admissions.
- The NDIA should establish:
  - a scope of practice for disability support workers to ensure consistent health care between participants' supported living environment and mainstream health services
  - information and training for planners to support NDIS participants' goals under the NDIS' Health & Wellbeing outcome domain.
- The NDIA should require support workers to have an appropriate level of expertise to support participants with complex and acute needs, as part of service provider registration requirements.
- The NDIA should align relevant NDIS policy settings to the *Primary Health Care 10 Year Plan* (Australian Government Department of Health 2023).

### Service Providers

- NDIS service providers should adopt clinical governance systems that:
  - maximise participants' choice and control
  - improve participants' quality of life and health outcomes
  - reduce negative health incidents and avoidable interactions with mainstream health services.

## Mainstream Health Services

- All health professionals should:
  - be trained in supporting people with disabilities, particularly those with complex and acute needs
  - provide information in accessible formats
  - allow additional time to treat people with disability.
- The Disability Reform Ministerial Council should:
  - establish national network of experts to assist mainstream health services to support people with intellectual disability
  - design protocols and support models to deliver the best outcomes for people with disability in mainstream health, allied health and acute health care services.

## Impact

- Active health planning improves participants' health and life outcomes.
- Proactive access to timely health care reduces the severity and impact of participants' fluctuating deterioration of health, loss of mobility and functionality.
- Timely access to mainstream health services would reduce participants' cost of care for the NDIA and state governments by reducing:
  - avoidable presentations to mainstream health services
  - NDIS plan costs required to support participants with preventable and chronic conditions (via lower staff ratios & less skilled support).

## 4. Information Sharing: Health & the NDIS

### NDIS Review Question

- How can governments work better to deliver a joined up system of inclusion and support for all Australians with disabilities (within and outside the NDIS)?

### Current Issues

- Mainstream health services do not share important information with participants with acute and complex needs and their service providers.
  - This disconnect risks participants' health and quality of life.
  - It also undermines NDIS providers' duty of care to participants.

### Recommendations

- The Disability Reform Ministerial Council should ensure NDIS participants' health information can be shared with relevant service providers in a timely way.

### Impact

- NDIS service providers can provide high quality support to participants with acute and complex needs when they receive appropriate information in a timely manner from healthcare providers.
- Coordination between health services and NDIS service providers will improve participants' continuity of care, health and quality of life outcomes.
- This approach can reduce participants' reliance on mainstream health services and allow for proactive whole of life support, guided by appropriately qualified service providers.

## 5. In Home Nursing

### NDIS Review Questions

- What steps could the NDIA take to make decisions about reasonable and necessary which are more consistent and fair?

### Current Issues

- The NDIA does not fund daily registered nursing clinical support to meet participants' reasonable and necessary needs.
  - The NDIA requires that these tasks are delegated to support workers.
- Achieve Australia employs a highly specialised workforce to meet the needs of the people we support, based on best practice models.
  - We are required to uphold the NDIS Practice Standards and Quality Indicators for participants' agreed supports.
  - Our Clinical Scope of Practice and Guidelines ensure that all tasks are delegated to staff who have the skills, knowledge and competency to carry them out safely.

### Recommendations

- The NDIA must ensure that the services and staffing required to support participants is consistent with clinical best practice for people with complex and acute needs.
- The NDIA should fund staff with the appropriate skills required to deliver clinical support and oversight for people with complex and acute needs including Clinical Nurse Educators, Registered and Enrolled Nurses.

### Impact

- Participants' health and safety will be protected by ensuring support is delivered by staff with appropriate qualifications.
- Service providers will be funded to deliver services that comply with their Clinical Scope of Practice and Guidelines and consistent with their duty of care to participants.



## 6. NDIS Plan Rollovers

### NDIS Review Questions

- How can reasonable and necessary be more clearly defined so that there is a shared understanding between participants and the Agency and participants have certainty about future funding?

### Current Issues

- The NDIA frequently rolls over plans for participants with acute and complex support needs without engaging with them, their family, carers or service providers.
  - The multi-disciplinary team of experts who support a participant have valuable and time sensitive insights about their care needs.
- Appropriate consultation is critical to creating a plan that supports participants' goals and quality of life, based on their current needs.

### Recommendations

- The NDIA should recognise and respect the legal and human rights of participants at all stages of the planning process.
- The NDIA should consult with the participant, their family, carers and appropriately qualified service providers when considering whether to roll over a participant's plan.
- The NDIA needs specialist expertise to plan and review funding for participants with complex and acute needs. This should include development of:
  - NDIS guidelines on reasonable and necessary supports for participants with intellectual disability and complex needs such as:
    - + active overnight support
    - + flexible respite options
    - + care that accounts for the effect of intellectual disability on participants' overall health
    - + increased care required as participants age.
  - an NDIA team with specialist expertise in intellectual disability and complex needs to assist with planning and reviews.

## 7. NDIS Quality & Safeguards Commission

### NDIS Review Questions

- How should governments and agencies be monitored to make sure they do what they say they will to support you? Who should perform this monitoring role?
- How can we build a system where the NDIS keeps improving based on evidence?

### Current Issues

- The NDIS Quality and Safeguards Commission (the Commission) is not fulfilling its responsibility to:
  - promote the health, safety and wellbeing of people with disability receiving supports or services
  - promote continuous improvement among all NDIS providers
  - develop a nationally consistent approach to managing quality and safeguards for people with disability receiving supports or services, including those received under the NDIS.
- Registered NDIS providers are held to a higher standard of service provision compared to unregistered providers.
- Compliance obligations for registered disability service providers require significant resources to manage compliance and reporting for:
  - the NDIS Practice Standards and Code of Conduct
  - in-house complaints management, incident reporting and external reportable incident procedures
  - employee screening
  - behaviour support and restrictive practice requirements.
- Compliance and reporting costs are 24/7 activities that are not factored into NDIS participants' plan so must be subsidised by registered service providers.

## Recommendations

- All NDIS service providers with more than one employee should be required to register with the Commission.
- Funding should be provided to support registered service providers to fulfill compliance and reporting requirements for participants with complex and acute needs.
- The Commission should collect data on the prevalence and diversity of complex and acute support needs for people with intellectual disability.
- The Commission should share data on incidents reported by NDIS service providers.
- Data gathered during NDIS provider registration should be used to improve the quality of services delivered to participants, particularly those with complex and acute needs.

## Impact

- The quality and consistency of services delivered to NDIS participants would improve.
- Service providers would be confident that the Commission applies a consistent approach to compliance and reporting.

## Case Study

Joan has cerebral palsy and is keen to access 10 hours of group-based support per week. Due to the complexity of her support needs, Joan needs to provide manual handling plans, medication documentation and mealtime management plans to access a compliant registered provider.

Joan needs to fund the development of these documents from her plan as well as fund the training of the staff to safely support her. This severely limits funding available for Joan's direct supports. Joan has been encouraged by planners and family to use unregistered providers instead.

Unfortunately, Joan must choose between:

- fewer hours of professional, compliant and quality planned direct support from registered providers
- more hours of non-compliant direct support from unregistered providers.

This approach limits Joan's choice and control.

## 8. SDA, SIL & Shared Supports

### NDIS Review Questions

- How can the scheme build goals that nurture connections to local community?
- How can you use your funding to help you connect with friends and family, learn new skills or try new things? What is keeping you from doing that now?
- How could the pricing structure be redesigned to reward outcomes rather than the volume of transactions?
- What steps could the NDIA take to make decisions about reasonable and necessary which are more consistent and fair?

### Current Issues

- People with complex and acute needs require specialised quality services and accommodation to support their quality of life.
- There is no capacity in current NDIS plans to plan and coordinate Specialist Disability Accommodation (SDA) and SIL funding to achieve intended outcomes for participants.
- A person's eligibility for SDA does not always align with their living preferences.
  - SDA funding is not linked to the daily living support funding necessary for a participant to live safely in their preferred home.
  - Appropriately qualified service providers can offer important insights in planning discussions to ensure a participant's needs and preferences for accommodation are met.
- The NDIA's current approach to shared onsite supports in SDA:
  - reduces participants' choice and control
  - is unsustainable for service providers
  - does not allow for appropriate duty of care arrangements across multiple service providers
  - does not provide sufficient funding to appropriately staff awake overnight shifts.

## Recommendations

- People with disability should be able to choose where they live with funding from the NDIA to:
  - choose the most appropriate services and accommodation, based on their preference for full independence or co-tenancy
  - support their mobility, support and adaptability needs
  - maximise their inclusion in the community
  - recognise and reduce barriers for people with intellectual disability and complex support needs to obtain their own housing.
- People with complex and acute needs should have access to support to plan their SIL and SDA arrangements, including transitional support.
  - This model should consider their specific needs for accommodation, in-home support, community access and participation support.
  - SIL support should be based on an integrated approach that combines clinical, health, social and disability support, delivered by appropriately qualified staff.

### NDIA

- The NDIA should fund an appropriately qualified service provider to act as a planning coordinator for groups of participants in shared accommodation with complex and acute needs.
  - This service provider would help make decisions on shared services required to meet the combined needs of participants.
  - Organisations that provide support coordination to participants should not also provide services to those participants.
- The NDIA should:
  - prioritise SIL and SDA for participants with the most complex and acute needs
  - fund 24/7 support and dedicated on-call services for participants with complex and acute needs living in the community
  - allow for adjustments to participants' living arrangements as their support needs, personal circumstances and the circumstances of their support network change, including as people age
  - adopt a flexible and responsive to SIL, recognising that a participant with complex needs may require unforeseen

adjustments as their personal circumstances or support network arrangements change

- include plan options to allow participants to exit SIL and choose co-residency arrangements instead
- fund modern accommodation and support for small groups of participants including apartment and co-resident support models which cater for their specific needs and circumstances
- fund support models that ensure all participants in shared accommodation can access their community, enrol in programs outside the house and engage with their peers
- fund implementation of safeguards for participants' accommodation and support
- invest in a model and workforce to support people with high needs to transition from clinical settings to community accommodation
- strengthen participants' choice and control by removing conflicts of interest between the provision of SIL, support coordination and accommodation management.

#### Service Providers

- Appropriately qualified service providers should be funded to provide overarching, trauma-informed support that protects a participant's autonomy and supports them to make informed decisions about their health, care and support across different systems and service providers.
  - The NDIS' funding model should reflect that this specialised support is tailored to each participant's complex and acute needs and cannot be delivered at scale.

#### Disability Reform Ministerial Council

- The Disability Reform Ministerial Council should provide clear market signals about housing needs and preferences for people with disability so SDA developers can invest in the right options at the right locations.

## Impact

- Services are more likely to achieve their intended outcome if participants' complex needs and history are taken into account when decisions are required on planning and delivering services.
- Appropriately qualified service providers can provide a rights-based approach to support participants' decision making, based on a detailed understanding of their baseline behaviour and health profile.
- Properly planned and coordinated SIL and SDA can help to:
  - improve participants' choice, safety, stability and inclusion
  - achieve participants' aspirations for community engagement, education and employment.
- Properly planned SDA and SIL allows people with disability to safely live at home for longer as they age.
  - People with a mild intellectual disability, in the absence of any other medical conditions, are now expected to live as long as their peers without disability.
  - Parents of children with disability should be confident that their adult child will be well cared as they age.

## References

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## HEAD OFFICE

### North Ryde

Suite 1.01, Level 1  
1 Epping Road  
North Ryde NSW 2113

1300 22 44 38  
[info@achieveaustralia.org.au](mailto:info@achieveaustralia.org.au)  
[achieveaustralia.org.au](http://achieveaustralia.org.au)

## REGIONAL OFFICES

### Epping

2 Brigadoon Court  
Epping NSW 2121

### Seven Hills

Suite 8  
197 Prospect Highway  
Seven Hills NSW 2147

### Newington

Unit 5, 2 Holker Street  
Newington NSW 2127

### Casino

The Chambers  
98 Walker Street  
Casino NSW 2470

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