TSA Tuberous Sclerosis Australia

Navigating the NDIS

A guide for people living with TSC (Tuberous Sclerosis Complex)

Contents

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About the NDIS

The National Disability Insurance Scheme (NDIS) is Australia's national support system for people with permanent and significant disabilities. It provides individualised funding to help people achieve their goals, increase their independence and participate more fully in daily life. The NDIS is designed to give participants choice and control over the supports and services they receive.

For individuals and families living with TSC (Tuberous Sclerosis Complex) the NDIS can offer crucial support. However, navigating the system can be complicated. Outcomes can vary depending on factors like who your planner is, where you live and how well your needs are presented. People can find the process confusing, inconsistent, and/or overwhelming.

This guide will be revised as necessary to reflect any changes resulting from the ongoing NDIS review (Oct 2025).

About this guide

This guide is designed to help people living with TSC, and those supporting them, navigate the NDIS and prepare for NDIS planning meetings. You can also find general information regarding TSC and the NDIS on TSA's (Tuberous Sclerosis Australia's) website.

In this guide, we cover:

- How to get the most out of your NDIS planning meeting
- What medical reports and assessments to take to the meeting to clearly demonstrate the functional impacts of TSC
- How to write a carer/impact statement that captures the full picture of care needs
- Goal setting
- Review meetings
- Helpful supports and services.

NOTE: Where we say 'you/your' in this resource, this generally refers to the person living with TSC and may be the person you care for rather than yourself. We may also use 'participant' to differentiate between the person living with TSC and the person caring for them.

The NDIS planning meeting

A key step in the NDIS journey is the **planning meeting**. This is the meeting where your needs, goals and daily challenges are discussed and where the types and amount of support you may receive are decided. Planning meetings occur when you first join the NDIS, when your current plan is due to be reviewed and when your circumstances have changed. These meetings can be in person, over the phone or online, and they are your opportunity to make sure that your support needs, or those of the person you care for, are clearly understood and reflected in the plan.

How can you get the most out of your NDIS planning meeting?

Preparation is key to getting the most out of your NDIS planning meeting. Here are some things to consider when preparing for your meeting:

> *Functional capacity, not just diagnosis, informs the funding. That's what planners need to see.*

- **Prepare ahead of time**
  Read through TSC and NDIS resources. Consider supports for health, communication, learning, behaviour, independence and community participation.
- **Understand and explain the complexity of TSC**
  TSC affects many areas of life - neurological, behavioural, physical and cognitive. A person living with TSC may have epilepsy, intellectual disability, autism, anxiety, sensory issues or other invisible symptoms. Explain how these challenges affect your everyday life, routines, safety and wellbeing.

TIP: TSA has prepared a document explaining TSC and its lifelong impacts, which can be attached to your NDIS application or shared at your planning meeting. This letter outlines how TSC affects functional capacity, common challenges, including TSC-Associated Neuropsychiatric Disorders (TAND) and the kinds of supports typically needed. Having this document on hand can help planners better understand the condition and why ongoing, multidisciplinary support is essential.

- **Consider who will attend the meeting**
  Consider taking a support person, such as a family member, advocate or therapist, who can help communicate your needs at the meeting. If you don't have someone available, ask your local area coordinator (LAC) about having an advocate present.
- **TAND and the impacts on your daily life**
  TAND is often misunderstood. Help your planner understand the behavioural, emotional and cognitive challenges you face. This may include sleep issues, aggression, anxiety, autism traits, attention difficulties or intellectual disability. You can find information about TAND on TSA's website, and the TAND checklist can help explain your experiences.

- **Collate all relevant documentation and take it to the meeting**
  Include medical reports (neurologist, cardiologist, geneticist or paediatrician), therapy assessments (occupational therapist, speech therapist or psychologist), education plans, behaviour support plans and a functional assessment. These help provide evidence of the impact of your disability and justify the supports you are requesting.
- **Take your banking and MyGov details**
  These may be needed to link your plan or make service bookings.
- **Tell your story in detail**
  Describe a typical day, including:
  - How seizures, fatigue or sensory issues affect your routine
  - How you manage medication, hygiene, meals, communication, appointments and social interactions
  - What support you need to stay safe and function at home or in the community
  - What you would like to do more independently, and what's currently holding you back
  - The emotional toll of managing a lifelong, complex condition.

TIP: Don't be afraid to speak openly. Many people living with TSC and their families feel they must 'hold it all together", but this is the time to talk honestly about your struggles, support gaps and goals.

- **Highlight family and carer needs**
  Carers often experience high stress due to medical complexity, behaviour support needs and lack of respite. Include the carer's perspective and ask for support, such as respite, carer training and in-home help.
- **Ask questions**
  If something doesn't make sense or seems unfair, ask for clarification. If a support is denied, ask: *"How can we make this work?"* It's okay to challenge decisions respectfully and ask for evidence or appeal options.

> *"It's not enough to list symptoms — (planners) need to understand how those symptoms limit daily life."*

Medical reports and assessments to bring to your NDIS planning meeting

Providing comprehensive documentation can help ensure the NDIS planner fully understands the impact of TSC on your daily life as well as your long-term needs. It is helpful if reports clearly identify support requirements and include consistent recommendations on what is needed to assist you, or the person you care for, to participate fully in social, learning and everyday life activities.

You can find a checklist of the recommended medical reports and assessments in Appendix 1.

Carer/impact statements for NDIS applications

When applying for NDIS support for someone living with TSC, a carer or impact statement can be a valuable addition to your application. Written by the person who provides day-to-day care, this statement helps the NDIS understand the real-life impact of TSC, not just on the individual living with TSC, but also on their carer and family.

While not a mandatory requirement, it is a chance to explain the challenges faced, the level of support provided and how caring responsibilities affect your own wellbeing as a carer. A clear and honest statement can help ensure that the NDIS planner sees the full picture and considers the appropriate supports. You can find tips and examples of what to include in your carer's impact statement in Appendix 4: Carer's statement documentation tips

TIP: Be honest. Describe what a bad day looks and feels like. The NDIS needs to understand the full impact of TSC on your life to allocate appropriate supports.

> *I outlined her needs from the moment she woke up to the time she went to sleep. It showed the level of care required every day.*

You may wish to use NDIS' 6 major functional capacity areas to guide you when writing your statement:

Functional capacity area	What to include
Communicating	Speaking, writing or using sign language/gestures to express yourself; understanding others; being understood by others.
Learning	Learning, understanding and remembering new information; practising and applying new skills.
Mobility	Moving around at home and in the community; getting in/out of bed or chairs; using arms or legs for movement and participation.
Self-care	Personal care, hygiene, grooming, eating and drinking, dressing, showering/bathing, toileting, health-related daily activities.
Self-management *(participants aged over 6 years)*	Organising daily life; planning, decision-making and problem-solving; managing money; independence in day-to-day tasks.
Socialising	Making and keeping friends; interacting with the community; play (for children); behaviour, coping with feelings and emotions in social situations.

You can use these categories to describe:

- What support is needed
- How often support is required
- The emotional and practical impact of having this support/not having this support
- Any costs involved in providing this support.

How to write a carer/impact statement for TSC

There is no prescribed format for a carer/impact statement. It can be a simple letter or a structured response. Either way, for each affected life area ('functional domain'), describe in simple terms:

- **What the person cannot do without support** due to their impairment (give clear, real-life examples).
- **How this impacts their day-to-day life, school, work or relationships** with peers and the community.
- **What supports are already being provided** (by family, carers, services or the community) and how effective they have been.
- **What additional supports are needed** (including frequency/intensity) and how these would build skills, maintain capacity or slow the progression of difficulties.
- **How these supports will improve participation** in social and community life and, where relevant, education or employment.

It is important to focus on the impairment and its impact, not just the medical condition. For example, instead of saying, "She has epilepsy due to TSC," explain how it affects daily functioning. For example, "Frequent seizures mean she cannot safely shower alone, and needs constant supervision when outside the home."

TIP: Outline the person's daily support needs from when they wake up until they go to sleep. This should describe what supports are required, when they are needed and who is currently providing them. Framing this information around the participant's functional needs, rather than the carer's workload, supports a stronger case for reasonable and necessary funded supports under the NDIS.

> ***When carers talk about needing help, it can be misunderstood. The focus must stay on the participant's support needs.***

Who can provide a carer/impact statement?

While a parent or primary carer usually writes the statement, anyone who provides regular support, such as a relative, teacher or service provider, can also write a carer statement. Their perspective can further show the full scope of support needed.

For examples of supports and services tailored to common challenges in TSC, see Appendix 3.

Goal setting for NDIS planning meetings

Setting clear and meaningful goals is a key part of your NDIS plan. Goals guide the supports and services you receive, helping you work towards greater independence, participation and quality of life. Well-defined goals make it easier to measure progress and adjust your plan as needed.

> *“Make sure you are clear about the goals you have and that the evidence you have supports the goals. That’s really important.”*

Why goal setting matters

- **Focuses your plan:** Goals ensure your supports are tailored to what matters most to you.
- **Guides funding:** Supports must be linked to achieving your goals to be approved as reasonable and necessary.
- **Measures progress:** Clear goals help track what’s working and where adjustments may be needed.

Tips for setting effective goals

- **Be specific and clear:** For example, instead of “improve social skills,” say “attend weekly community group and initiate conversation with at least one new person each session.”
- **Make goals measurable:** Use specific, trackable outcomes such as, “increase participation in community activities from once a month to twice a week over six months.”
- **Focus on what’s important to you:** Choose goals that reflect your priorities, interests and needs.
- **Set achievable steps:** Break larger goals into smaller, manageable steps to build confidence and momentum.
- **Include short and long-term goals:** Short-term goals can be achieved in the near and medium-term future; long-term goals focus on bigger changes.
- **Link goals to supports:** Make sure the supports you request clearly help you work towards your goals.

You can find more goal-setting tips, including examples, in Appendix 5.

NDIS plan review meeting

The NDIS plan review meeting is an opportunity to assess how well your current supports are meeting your needs and to plan for the upcoming year. It allows you to update your goals, request necessary changes, and ensure your funding aligns with your evolving circumstances. Preparing thoroughly for this meeting helps you advocate effectively and get the most out of your NDIS plan.

> *Every review feels like they expect she's suddenly better. We have to constantly reiterate that this is a permanent, significant disability.*

Getting the most out of your NDIS plan review meeting

- **Request a face-to-face meeting** before your current plan ends. This allows for better communication and ensures your needs are fully understood. If possible, avoid having the review over the phone.
- **Clarify what's required by your Local Area Coordinator (LAC)** or planner before the meeting. Be prepared with all relevant documents, reports and evidence to support your goals and funding needs.
- **Gather assessment reports and quotes from your providers and therapists** ahead of time. Having up-to-date professional recommendations strengthens your case for supports in the new plan.
- **Review your current plan in detail** - note what supports worked well and what didn't and consider any changes in your needs or goals since your last plan.
- **Set clear, achievable goals** for the next plan period. Think about both short-term and long-term goals, and how the supports requested will help you achieve them.
- **Bring a support person or advocate** if you want extra help during the meeting to ensure your voice is heard and your needs are communicated clearly.
- **Be honest and specific about your support needs** and challenges. Concrete examples of daily tasks or situations where support is needed can be very helpful.
- **Discuss informal supports and how they fit into your plan**. This helps show the full picture of your support network.
- **Ask questions** if you don't understand parts of the plan or the process - your planner is there to help you.
- **Keep records of everything discussed and any agreements made** during the meeting for future reference.

NDIS decision review process

If you disagree with a decision made by the NDIS, you can request an internal review. This process allows a different NDIA (National Disability Insurance Agency) officer to assess the original decision. You must submit your review request within 3 months of receiving the decision in writing. If you're still dissatisfied after the internal review, you may seek an external review by the Administrative Appeals Tribunal. Find more information about this process on the NDIS website.

Useful links and resources

Association for Children with a Disability (ACD)

Provide NDIS information and advocacy to support families of children with disabilities. Victoria-based but they operate a national help line.

NDIS

Here are some links to useful guides on the NDIS website

- A guide on how NDIS supports work
- Changing your plan
- How the planning process works
- NDIS booklets and factsheets
- Requesting a review of a decision
- Setting short and long-term goals

TAND Checklist

A tool designed for individuals and families living with TSC to identify and understand TSC-Associated Neuropsychiatric Disorders. The Checklist can be used to screen, quantify and guide support and healthcare discussions.

TAND Toolkit

The TAND Toolkit was created by the international TAND Consortium together with families and professionals from around the world. It is designed to help people living with TSC and their families better understand and manage TAND. The toolkit is organised around 7 natural TAND clusters, plus an eighth wraparound cluster about wellbeing and family relationships.

The Frankie Foundation

Parents can apply for small grants through the foundation to help children under 12 access essential therapies when NDIS funding runs out. If the application is successful, the foundation pays the therapy bill directly.

TSA Nurse Service

TSA operates a telehealth nurse service staffed by a Registered Nurse to provide information and support to people living with TSC or a possible diagnosis of TSC and their families and carers. The service also assists clinicians caring for people with TSC. Health care professionals can contact the nurse for TSC-specific advice and recommendations on clinicians and specialists experienced with TSC across Australia. You can book a call with the TSA nurse, call 1300 733 435 (Australia only) or email nurse@tsa.org.au.

TSA

TSA is the only charity in Australia supporting people living with TSC. By providing knowledge, support and connections, we aim to create a better life and a more hopeful future for everyone in Australia affected by TSC. TSA supports individuals and families affected by TSC, fostering a community for shared experiences and learning. We connect people to expert health care professionals and services. Collaborating with our Medical Advisory Panel and global researchers, we seek new treatments, screening options, and ultimately, a cure for TSC.

We raise awareness, advocate for better health care access and partner with TSC International, Rare Voices Australia and Tuberous Sclerosis Complex New Zealand. TSA is the trusted go-to resource for information, advice and support for everyone in Australia affected by TSC.

TSA Website

Visit TSA's website for up-to-date information on TSC, including resources for people living with TSC and families and caregivers, materials for health care professionals and details on TSC signs, symptoms and treatments.

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Appendices: Checklists, tables and documentation tips

Appendix 1: Medical reports and assessments checklist

Having the right medical reports and assessments at your NDIS planning meeting can help clearly demonstrate the impact of your disability and the supports you need. These documents provide objective evidence for your requests and ensure the planner has accurate, up-to-date information to base decisions on. The following checklist will help you gather the most relevant reports and assessments so you can attend your meeting well-prepared.

Neurological and Developmental Reports

- ☐ Neurologist report (especially relating to epilepsy, seizures and brain involvement).
- ☐ Epilepsy management plan (if applicable, including the need for supervision and impact of epilepsy on safety).
- ☐ Developmental paediatrician assessment - this should highlight developmental and behavioural challenges, specific diagnoses (such as autism or intellectual disability) and affected areas of daily life (such as sleep disorders or restricted eating). Where needed, it should provide suggested evidence-based recommendations for developmental and behavioural interventions.
- ☐ Psychiatric or behavioural specialist reports (including completed TAND checklist, if available).
- ☐ Cognitive assessment (such as from a psychologist).

Therapy and Functional Assessments

- ☐ Occupational therapy report (focusing on daily living, sensory issues and independence)
- ☐ Speech pathology report (especially if there are communication or feeding issues)
- ☐ Psychology report (highlighting behavioural, emotional or social challenges)

Medical and Specialist Reports

- ☐ TSC diagnosis confirmation (from a geneticist or specialist)
- ☐ Renal (kidney) scans or a nephrologist report
- ☐ Cardiologist or respiratory specialist reports (if heart or lung involvement exists)
- ☐ Dermatologist report (for significant skin manifestations)

Daily Living and Support Needs

☐ Functional capacity assessment (can be completed by an OT or support coordinator)

☐ School or educational support plan (Individual Education Plan or equivalent)

☐ Carer statement or support letter (outlining day-to-day support requirements)

☐ Current therapy provider reports (progress notes, treatment plans, and goals)

Other Useful Documentation

☐ NDIS Access Request Form (ARF) and supporting evidence

☐ Reports from previous NDIS plans (if applicable)

☐ Medication summary from your GP or pharmacist

☐ TSA NDIS support letter

Appendix 2: NDIS review meeting checklist

Preparing for your NDIS review meeting is an important step to ensure your plan continues to meet your needs and goals. This checklist will help you get organised, track your progress and communicate effectively with your planner or support coordinator. By reviewing what's worked well, identifying challenges and setting clear goals, you can make the most of your review meeting and ensure your supports are tailored to your specific needs.

Before the Meeting

☐ **Review your current NDIS plan**
Check your goals, funding supports and services. Note what worked well and what didn't.

☐ **Gather evidence**
Collect reports, therapy updates, medical letters, progress notes, and receipts.

☐ **List your achievements**
Write down improvements or milestones reached since the last plan.

☐ **Identify challenges**
Note any areas where support wasn't enough or goals weren't met.

☐ **Think about new goals or changes**
Consider new supports, services or goals you want in your next plan.

☐ **Prepare questions**
Write down any questions or concerns to discuss during the review.

During the Meeting

☐ **Discuss each goal**
Talk about progress, challenges and whether goals need updating.

☐ **Review current supports and services**
Are they adequate? Do you need more or different supports?

☐ **Share evidence**
Provide any reports or documents that show your progress or needs.

☐ **Clarify funding**
Ask about funding levels and what can be adjusted or added.

☐ **Set new or updated goals**
Make sure they are SMART (Specific, Measurable, Achievable, Relevant, Time-bound).

☐ **Confirm next steps and timeline**
Understand when the updated plan will be finalised and how to follow up.

After the Meeting

☐ **Get a copy of the updated plan**
Review it carefully to ensure it reflects the discussion.

☐ **Provide any additional information promptly**
If requested by the NDIS planner.

☐ **Schedule reminders**
For the next review or important appointments related to your plan.

☐ **Start implementing supports**
Begin accessing or arranging services as per the new plan.

☐ **Keep records**
Maintain documentation of all communications and progress.

Appendix 3: Helpful supports and services for people living with TSC

The supports and services below are tailored to common challenges associated with TSC, such as epilepsy, developmental delay, autism traits and TAND. Please note that not all services listed may be funded by the NDIS. However, including any that are required for participating in daily life in your planning discussion can help ensure your needs are fully considered.

Support/Service	How it may help
Assistive Technology	Devices like communication aids, sensory supports, visual schedules and seizure monitors help manage symptoms and promote independence.
Community Activities and Hobbies	Encourages interest development, confidence and social engagement. Includes arts, music or structured programs with support as needed.
Community Participation and Education Support	Helps build confidence, social skills and access to community groups, education or training. Useful when executive functioning, social anxiety or autism traits impact participation.
Health and Wellness Activities	Activities like swimming or gym help with regulation, sleep, energy levels and motor skills. Support may be needed to initiate, attend and stay engaged.
Nutrition	Helps manage food sensitivities, fussy eating (often linked with autism or sensory issues) and supports healthy growth. May collaborate with an occupational therapist (OT) to develop meal plans or recommend meal prep services.
Occupational Therapy (OT)	Supports the development of fine and gross motor skills, daily routines, emotional regulation and sensory processing. OTs help build independence in tasks such as dressing, hygiene, cooking and transitioning to new environments. Can help address sensory processing issues in TSC through tailored strategies.
Personal Care Support	Assists with medication routines (taking many medications is common in TSC), hygiene (including continence aids), meal preparation, medical appointment coordination and home tasks. Provides support for intellectual disability, autism or may be epilepsy-related.
Physiotherapy	Helps with movement, balance, coordination and pain management.
Psychology, Counselling and Behaviour Support	Assists with managing TAND symptoms such as anxiety, depression, aggression and attention difficulties. Behaviour support practitioners can also develop Positive Behaviour Support Plans to manage challenging behaviours and improve quality of life.
Speech Therapy	Helps with verbal and non-verbal communication challenges common in TSC. Supports expression of needs, following instructions and social skills development.
Supported Independent Living (SIL)	Provides a structured, safe and supportive group home environment while promoting independence for individuals with high support needs.
Transport	Supports access to therapy, appointments, group centre-based activities and community activities. Especially useful for people with seizures or executive functioning challenges.

Appendix 4: Carer's statement documentation tips

A carer's statement is your opportunity to explain the level and type of support you provide as a carer to the person you care for, and the impact this role has on your own life. The NDIS uses this information to understand the participant's daily support needs and the extent of informal care provided. The way these needs are described can make a big difference to how they are understood. The following examples show language that can clearly and accurately convey support requirements in a carer impact statement. Frame everything around the participant's *functional capacity*. For example, instead of saying, "I need help because I'm exhausted." Say: "The participant requires daily assistance with all personal care, and current informal supports are unsustainable."

1. Overview of TSC and its impact

Describe the participant's diagnosis and how TSC affects their daily functioning. Include details like epilepsy, intellectual disability, autism, sensory needs and other relevant *challenges.*

Example
"My son Jack lives with TSC, which causes seizures, developmental delay, and severe sensory issues. He requires 24/7 supervision due to frequent seizures and a high risk of injury."

2. Daily support needs (structured by functional domains)

Use the following format under each NDIS domain. Be specific about what support is needed, who provides it and how often.

Daily Living

Describe tasks requiring assistance, such as dressing, toileting and bathing. Who helps and how frequently?

Example
"Jack requires full physical assistance with dressing, showering, and toileting. I provide this care daily as he cannot manage hygiene independently due to intellectual disability and motor coordination difficulties."

Home

Include safety concerns, supervision requirements, meal preparation and cleaning support.

Example
"Jack cannot be left alone in the kitchen due to the risk of burns or seizures. I prepare all meals and manage cleaning, as he is unable to safely participate."

Continue similarly for the remaining domains: *Health and Wellbeing, Lifelong Learning, Work, Social and Community Participation, Relationships, Choice and Control.*

3. Emotional and physical impact on carer

Explain how caring affects your mental and physical health, stress levels, sleep, work and social life.

> **Example**
> "The stress of constant vigilance has significantly impacted my mental health. I have not slept through a full night in over a year because I need to monitor Jack's seizures. I have had to leave my job to provide full-time care."

4. Informal supports

Describe any help you receive from family, friends or community services.

5. Sustainability of current care

State whether you can continue this level of care long-term and any concerns about burnout or additional supports needed.

Table 1: NDIS language/framing for carer impact statements

NDIS decision-making is based not just on diagnoses but on functional impact - how the disability affects daily living. Using NDIS terms helps planners align the participant's needs with reasonable and necessary supports.

Everyday language	NDIS language/How to frame it	Why this helps
My child needs help with everything.	The participant requires support with daily living tasks, including hygiene, dressing and meal preparation, due to cognitive and physical impairments.	Specifies *which* tasks and why, showing clear functional impact.
He gets tired easily.	Fatigue significantly limits the participant's ability to participate in community and learning activities without scheduled rest breaks.	Connects symptom to *functional limitation* and *need for support.*
She's always anxious.	Anxiety affects the participant's ability to engage socially and maintain routines, requiring regular therapeutic intervention and behavioural support.	Explains how the symptom *impacts daily life* and *justifies supports.*
We need help with bathing and dressing.	Supports are required for personal care activities to ensure safety and independence due to limited fine motor skills and sensory sensitivities.	Links supports to *safety* and *functional challenges.*
He can't do schoolwork.	The participant requires educational support to assist with comprehension, task initiation and maintaining focus due to intellectual disability and executive functioning challenges.	Focuses on *specific educational barriers* and the need for assistance.
I look after him all day.	The carer provides ongoing support throughout the day, including medication management, behaviour support and assistance with mobility, which impacts their own wellbeing and capacity.	Describes the carer role with *specific tasks* and acknowledges the impact on the carer.

She has seizures.	The participant experiences frequent seizures that affect safety and require supervision and medical management to reduce the risk of injury.	Details *risk and supervision needs* tied to seizures.
He's non-verbal.	Communication challenges require augmentative and alternative communication supports to enable the expression of needs and social participation.	Emphasises *functional communication needs* and support options.
We just want her to be more independent.	The goal is to increase independence in daily living and community participation through targeted therapy and assistive technology.	Links goals with *functional outcomes* and *support strategies.*
He can't make decisions.	The participant requires support with decision-making and understanding choices to exercise choice and control over daily activities.	Reflects NDIS emphasis on *choice and control.*

Appendix 5: NDIS goal-setting documentation tips

Remember, setting a goal doesn't guarantee funding for a specific support; instead, NDIS will consider supports that help you overcome disability-related barriers to pursue your goal.

1. Participant's interests and strengths

What does the participant enjoy? What are they good at?

Example

Loves music and water play. Enjoys social interaction in safe and structured settings. Responds well to visual supports.

2. Short-term goals (6–12 months)

These should be achievable within the next NDIS plan and help build daily living skills, confidence or social connections.

You may like to structure your short-term goal setting under the following headings:

- Goal
- Why this goal matters
- What support is needed to achieve this goal.

Example

Goal: Build confidence and independence with personal care routines.
Why this goal matters: To reduce reliance on parents and increase daily living skills.
Support needed: Occupational therapy sessions, visual schedule, personal care worker at home.

3. Medium/long-term goals (1–2 years)

Reflect broader aspirations like independence, education or social inclusion.

You may like to structure your medium/long-term goal setting under the following headings:

- Goal
- Why this goal matters
- What support is needed to achieve this goal.

Example

Goal: Increase community participation and social skills.
Why this goal matters: To reduce isolation and develop meaningful connections.
Support needed: A Support worker to assist with community access and joining local group activities.

5. How will we track progress?

List ways progress will be reviewed.

Example

Progress notes from OT and speech therapy, data from assistive technology, reports and feedback from other allied health professionals (physiotherapist, social worker, behaviour support practitioner), self-reporting/participant journals, carer diary.

6. Factors to highlight during the planning meeting

- Participant's challenges and how they impact daily life.
- Support needs aligned with each goal.
- Importance of funded support to work towards these goals.
- Informal supports are not sustainable long-term.

Tips for goal writing (using NDIS language)

- Make goals person-centred: "I want to…"/"Alex would like to…".
- Link each goal to skill development, independence or community participation.
- Show why the goal matters (to improve safety, reduce risk, increase independence).
- Be realistic but aspirational.

NDIS will review your goals at reassessments and ask questions like

- "How are you going with your goals?".
- "What's working well? What could improve?".

Table 2: NDIS language/framing for goal setting

Everyday language	NDIS language/How to frame it	Why this helps
I want to communicate better.	Increase my ability to communicate basic needs by attending weekly speech therapy sessions for 6 months.	Demonstrates a clear, measurable goal linked to a therapy that targets communication skills.
I want to be more independent in the morning.	Develop a morning routine checklist with an occupational therapist to improve independence in getting ready for the day by November 2025.	Shows how the support will build daily living skills and promote independence.
I want to make more friends.	Safely participate in a local art group within 9 months to build social skills and confidence.	Frames social participation as a measurable goal linked to community inclusion and skill development.
I want to feel less anxious.	Attend monthly psychology sessions to manage anxiety related to medical appointments and seizures.	Explains the need for mental health support linked to specific triggers and outcomes.
I want to eat better.	Work with a dietitian to develop a meal plan that accommodates food sensitivities and nutritional needs within 3 months.	Focuses on targeted nutritional support addressing health-related needs specific to TSC.
I want to get fitter.	Learn and practise 2 new physical exercises with a physiotherapist to improve balance and reduce muscle stiffness within 6 months.	Connects physical activity goals to therapy that addresses TSC-related motor challenges.