

Navigating the NDIS: Advice on Advocating for your Child and Making the Most of their Support Plan.

What is the NDIS?

The NDIS is the National Disability Insurance Scheme. It was established as a world first approach to disability support. It puts people with disability at the center of decision-making.

Key phrases to keep in mind when dealing with the NDIS and their representatives. They focus on providing services that are REASONABLE AND NECESSARY supports. The focus is also on INDIVIDUAL CHOICE AND CONTROL for their supports.

As an Advocate for your Child - YOU are the expert on your Child!

Only YOU, as parents and carers can tie together what your child's daily life and challenges look like, so you need to educate yourself to be able to communicate this.

The LAC (Local Area Coordinators) can suggest therapies, but they do not know the individual needs of your child. They do not know how they are at home and in their different regular environments.

The more information you give during the plan building process, the better!

The NDIS is there to facilitate people with disabilities being able to have the same life experiences, independence, participation in the community and quality of life as their same aged peers! This is anyone's human right.

KNOW your rights and KNOW NDIS legislation!

Use the NDIS website! This information is **all available on NDIS website** – under “plan review” and “operational guidelines”.

What are “Reasonable and Necessary” Supports?

The NDIS funds a range of supports and services which may include education, employment, social participation, independence, living arrangements and health and wellbeing – BUT –

- must be related to a participant's disability
- must not include day-to-day living costs not related to disability support needs, such as groceries* (but can include consumables)
- should represent “value for money”
- must be likely to be effective and work for the participant, and
- should take into account support given by other government services, your family, carers, networks and the community – and individual circumstance

Plan end date is coming... what do I do for a review?!


Firstly, don't worry. If your plan reaches its end date and your new plan hasn't been finalised yet, your current plan will be automatically extended for up to 12 months - there are not any gaps in funding or supports.

The budget will stay the same when the plan is automatically extended until you are contacted and a new plan review occurs and is finalised.

If your plan is close to or past its end date, **you do not need to do anything** and you will not have a funding gap – the NDIS will contact you to schedule your plan review meeting.

BUT if you are running out of funds early, you can apply for an early review for **change of circumstance**.

Preparing for plan creation and reviews



The screenshot shows the NDIS website layout for plan creation and reviews. It features three main sections connected by a vertical line with arrows pointing downwards. Each section includes an icon, a title, a brief description, and a link to a resource page.

- Creating your plan:** Icon of two people talking. Text: "Your plan is a written agreement worked out with you. Everyone's plan is different. We will ask questions about how you are going in different areas of your life, what goals you would like to pursue and what kind of help and support you need. This will help us to develop a plan that provides the right support for you." Link: [Creating your plan](#)
- Using your plan:** Icon of a document with a gear. Text: "Once you have your plan, there are people who will help you start it. Find out the different types of budgets, and how to use the myplace portal." Link: [Using your plan](#)
- Reviewing your plan and goals:** Icon of a person with a calendar. Text: "Your plan review is the opportunity to check your supports are working for you and they are helping you pursue your goals." Link: [How to review your plan and goals](#)

There is a lot of information on the NDIS website. There are videos, checklists, and it is well-formatted. Refer to these, as this is what is built in policy and legislation and are the framework of your child's rights.

Sometimes, you may be given different verbal information by staff... The website is what is policy and legislation. Believe the website.

Before the plan meeting...

Identify the key areas your child is finding challenging

Observe your child in the home, and in different environments

Ask other care-givers and important people in the child's life

What do they find most challenging?

What is causing the biggest impact to family life?

What are their biggest barriers to doing what same-aged peers are doing?

Some questions to consider...

Are they Sensory seeking?

Are they sensory avoidant? – clothes, food, noise, smells

Are they needing work with gross and/ or fine motor skills?

Are they struggling with verbal and/ or non-verbal communication?

Are they struggling with speech clarity (being understood)?

Can they follow instructions in line with what is developmentally appropriate?

Do they have imaginative play skills and representation?

Are they interacting with other children?

Do they respond better to visuals than words?

Would they respond to using an AAC (Augmentative and alternative Communication)

Can they cope with everyday routines?

Daily living skills? Toileting? Washing? Dressing?

Do I feel they are safe going into the community?

How do they look in relation to their SAME aged peers?

Examples of funded supports

Occupational therapy (OT), play therapy

Psychology

Speech Pathology (Speech therapy), Mealtime therapy

Music therapy

Art therapy

Physiotherapy

Hydrotherapy

Community support worker

Therapy assistant

Augmentative and Alternative Communication devices – Proloquo2go, Touch Chat

Consumables – books, visual supports, continence supports

Which challenge aligns to which support?

There are MANY different therapies and supports available, to support your child to work on their challenges

Your child is an individual, and thus has an individual profile of needs, and also is influenced by their particular environment

There is no right or wrong plan of therapies – it is what **you** deem your child needs to best work on their goals, where you are informed by professionals and therapy approaches

The plan needs to be achievable and sustainable for your family circumstance

Gather reports and evidence

These are harsh – what does the person look like, unsupported, on their worst day (as this is what will happen if they are not funded with the appropriate supports!)

Functional capacity assessment (OT)

Speech assessment

Other therapists reports and recommendations

School / kindy/ childcare assessments and observations

Ask existing therapists to supply a written **BUDGET** which includes recommendations for therapy duration and frequency

Write some notes from a carer perspective

This is **hard – but important to paint a picture**

“As a result of their disability, I (for example)…”

- Cannot work, or work usual hours
- Cannot attend medical appointments, dentist
- Cannot go on a social outing with my partner
- Cannot attend usual birthday parties

Be blunt. This is life.

Create a list of goals

From **NDIS website**:

- ▶ Your goals are not directly linked to your NDIS funding. Your NDIS funding is aimed to provide you with the supports you need for your disability. These supports may assist you to increase your independence and pursue your goals. You can also be supported through informal supports like family, friends, and by mainstream or other community services.
- ▶ Setting a goal in your plan doesn't mean we must give you funding to pursue it. Setting more and bigger goals doesn't mean we will give you more and bigger funded supports.
- ▶ Setting a goal about a detailed type or amount of support you might want doesn't mean we have an obligation to fund that support or in that amount

Examples of clear Goals

- Increase emotional regulation
- Increase behavioural regulation
- Increase communication and understanding
- Increase self-help/ daily living skills in the home
- Build and maintain relationships with others
- Access and participate in the community
- Build independence

Think: How do you intend to do it? Speech ? behavioural therapy? Music therapy, etc?

Family circumstance must be considered

- ▶ *“The NDIS is a new way of providing individualised support for people with disability, their families and carers. The NDIS will provide all Australians with a permanent and significant disability, aged under 65, with the reasonable and necessary supports they need to **live an ordinary life**”*

For many parents after diagnosis, their family are living a life very far from the ordinary life

In fact, it is a life of day-to-day survival and a family in crisis, where intensive intervention is needed and reasonable to bridge the gaps and provide the therapies and support needed for the child their family to bridge the gap between the child and same-aged peers.

In section 4.4.2 in the NDIS operational guidelines, in relation to the National Disability Insurance Scheme Act (2013)

- ▶ *people with disability should be supported in all their dealings and communications with the NDIA so that their capacity to exercise choice and control is maximised in a way that is appropriate **to their circumstances and cultural needs** (section 4(9))*

If the plan is not right?

A plan may come back with insufficient funding for what you asked for, and may not include some core supports

If you don't agree with the provided plan, you can ask for an **internal review**.

Having an internal review means someone who wasn't involved in creating the plan will review the decision to approve the plan.

They'll consider if the NDIS delegate made the right decision under the laws for the NDIS.

Once receiving a new plan, a participant has 3 months to ask for an internal review.

BUT – you can apply for a “change of circumstance” review meeting **at any time** – you just need evidence and reports to prove this