



# Navigating the National Disability Insurance Scheme (NDIS)

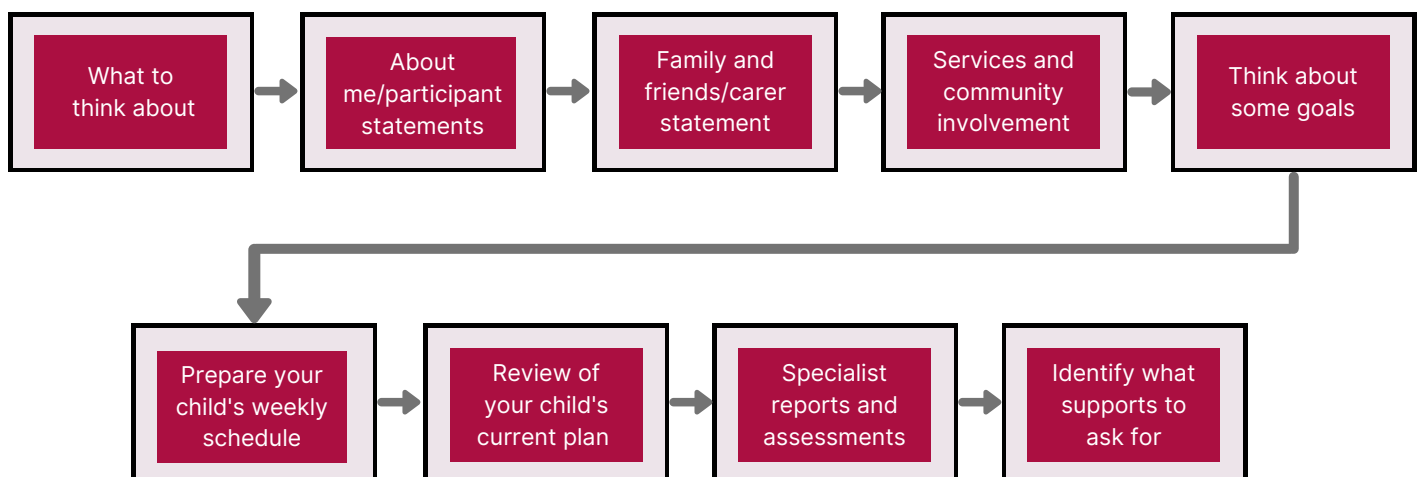
The NDIS can seem overwhelming at times. SWAN has developed a series of fact sheets to assist our families:

- Becoming an NDIS participant
- Background to a planning meeting
- Preparing for your child's NDIS planning meeting
- The planning meeting
- Useful tips



## Preparing for your child's NDIS meeting

It can be overwhelming thinking about and preparing for your child's NDIS planning meeting. This fact sheet breaks the steps down for you. It suggests information that may be useful to compile for your child's planning meeting.



## a) What to think about

If you have information, assessments and reports you can send them to your planner before your NDIS planning meeting. This can help planners understand your child's needs and those of their family's circumstances. You can list how your child's disability and condition impacts their daily life in a short summary (dot pointing the symptoms of the medical condition which relate to the disability e.g. non-verbal, incontinent etc.) This can be helpful for planners who have never come across your child's rare condition before.

Provide evidence reports and assessments (if applicable) that support your child's goals, progress and their needs, going forward into their next NDIS plan.

Creating a preplanning document can be useful. This can include:

- About me - Participants statements – refer to Appendix 1
- Family and friends - Carers statement – refer to Appendix 2
- Services and community involvement - formal and informal supports – refer to Appendix 3
- Current plan - refer to Appendix 4
- Goals - refer to Appendix 5
- Undiagnosed or rare genetic condition short summary – refer to Appendix 6

Your child's preplanning document should demonstrate that the requested supports are “reasonable and necessary”. Think about what supports you want in your child's plan and how often you wish to receive these supports. The supports should be linked to goals. Ideally, these goals could be referenced in supporting documents from therapists/support services. They should make references to any recent assessments (if applicable) and demonstrate why the supports are needed and the goals that the supports will help accomplish. Your preplanning document should also state how you wish the supports to be managed in your child's NDIS plan - refer to Appendix 7.

## **b) About me (prepare a participant's statement)**

Write about what life is like for your child (as the NDIS participant), from their perspective. Be honest about how they find life. You can state things like:

- Living arrangements
- Formal and informal supports in place
- Activities your child enjoys
- Tasks your child needs support with

## **c) Family and friends (prepare a carer's statement)**

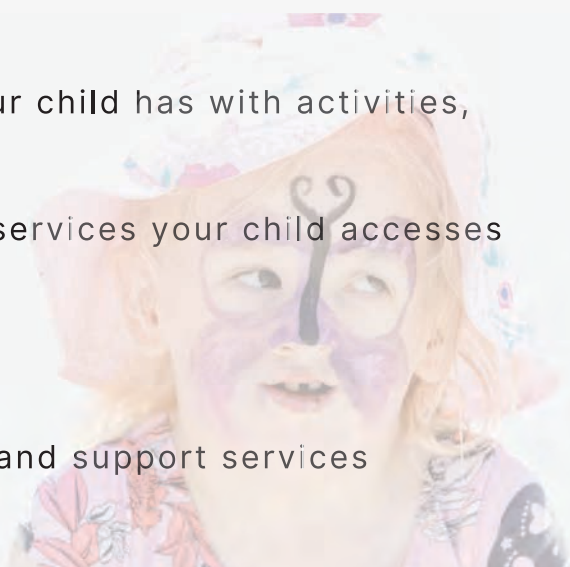
Write about what life is like for you as your child's carer. Include things from your perspective like:

- How you care for your child and what supports you provide to assist them
- What activities your child enjoys
- What supports would make it easier for you to build your child capacity and support their goals
- What you find difficult about caring for your child
- How you think you cope with looking after your child
- Be honest about what life is like living with and caring for your child

## **d) Services and community involvement**

Write about what community involvement your child has with activities, and what services your child engages with.

- What community supports, activities and services your child accesses
- How these services support your child
- How often your child frequents them
- Who accompanies your child to activities and support services



- What school your child attends
- What health professionals and therapists support your child
- What other organisation/services or people support your child

#### **e) Think about some goals**

Think about goals you would like your child to achieve in their NDIS plan. Your Planner/LAC/ECEI coordinator will either adopt these, modify them or suggest some other goals for your child.

- Short-term goals
- Longer-term goals and aspirations
- Goals should be realistic, relevant and specific to your child
- Your child's NDIS plan should reflect their goals

#### **f) Prepare your child's weekly schedule**

- Think about what activities your child does in the week (you can document this in your preplan)
- Think about how much you are involved in helping your child to engage in these activities
- If your child does not sleep well, document when they are awake

#### **g) Review of your child's current plan**

- What would you like to keep in your child's current NDIS plan?
- What would you like to change in your child's current NDIS plan?
- Did your child meet their NDIS goals? If not why not?
- Did you have enough funding to access the supports required in your child's current NDIS plan for them to meet their goals?
- If you underspent your child's current NDIS plan, state the reason why

## h) Specialist reports and assessments (evidence)

- Reports, letters and assessments from clinicians, therapists and people supporting your child will help the NDIS to understand your child's needs. They can provide evidence to justify the supports for the funding requested in your child's planning meeting. They are particularly important as the NDIS is usually not familiar with undiagnosed or rare genetic conditions.
- Reports/letters should support your child to meet their NDIS goals
- Supporting professionals should recommend supports that are "reasonable and necessary"

## i) Identify what supports to ask for

- **Professionals advice** - take the advice of the professionals that work with your child, such as allied health professionals. They will recommend supports in their letters and reports, often based on recent assessments of your child.
- **What is working well** – if things are working well, you might just be able to ask for the supports in your child's current NDIS plan to be rolled over to their next plan.
- **What would you like to change** – are there supports that are not in your current plan that are "reasonable and necessary" that would assist your child in meeting their NDIS goals? Think about services or activities your child would benefit from engaging in. Know what supports you want for your child and be clear about it.
- **What supports does your child want** – if your child is able to tell the Planner/LAC/ECEI coordinator what supports they would like in their plan, be guided by them if the supports are "reasonable and necessary".
- **Look at the NDIS pricing guide** – to see what type of supports that are funded and the approximate cost of the support item (please note the pricing guide changes about twice per year).
- **Formal supports vs informal supports** – think about what you already have in place that is working well or not working well as the case may be.

- **Transition phases** – is your child coming up to a transition point in their life? E.g. kinder to school, school to further education or work, different living arrangements. This is an area where the NDIS can really make a difference.
- **Think about the gaps** – what is a typical child of the same age doing? In October 2014 there was a report released by the Independent Advisory Council to the National Disability Insurance Scheme - Reasonable and Necessary Support across the Lifespan: An Ordinary Life for People with Disability. The report is still relevant today and Appendix A1-A11 of the report identifies the key features of lifespan for various age groups. This identifies and gives a good comparison on what a “typical child/adult” of the same ages in doing in that stage of life compared to a child/adult with disability.
- **Talk to your friends and networks or talk to the experts at SWAN!**

## References and further reading

Independent Advisory Council to the National Disability Insurance Scheme - Reasonable and Necessary Support across the Lifespan: An Ordinary Life for People with Disability

<https://bit.ly/3cs91v7>

NDIS pricing guide

<https://www.ndis.gov.au/providers/price-guides-and-pricing>

National Disability Insurance Scheme Act 2013 – Section 34 Reasonable and necessary

<https://www.legislation.gov.au/Details/C2018C00276>



## Disclaimer

*The information in our fact sheet series is correct to the best of our knowledge at the time of writing. Please note that NDIS information is subject to change, including without notice, and SWAN Australia cannot be held accountable for any misguided or false information. We encourage you to do your own planning and research.*

*Planning for your child's NDIS meeting, using the advice reflected in our fact sheet series is what SWAN Australia considers important when preparing for your child's NDIS planning meeting and is independent of the NDIA's views.*

## Appendix 1 - About me - Participants statement (example only)

### XXX, NDIS participant

XXX is almost XXX years old and has a rare genetic condition called XXX syndrome (see attached plain English fact sheet/dot points). There are only XXX people who live in Australia with their genetic condition and less than XXX people in the world. They live at home with their mum XXX, dad XXX, and sister XXX.

XXX attends XXX School as a full-time student in grade XXX. They don't like school as they struggle socially and spend most lunchtimes and playtimes not playing with anyone else.

XXX enjoys 1:1 swimming session when they are in the mood. Some of XXX's favourite things to do are dancing, singing and listening to music. XXX enjoys having their disability support worker interact with them and develop their independence in the home, as well as out in the community.

## Appendix 2 - Family and friends - Carer 's statement (example only)

### XXX, NDIS participant's mother

I find caring for XXX challenging. Their behaviour can drain me and some days I am emotionally pushed to my limit. XXX often refuses to do tasks and activities which I find frustrating. XXX is often more compliant for their support workers and teachers than for their family in their home environment.

I constantly worry what the future might hold for XXX, particularly around their safety, as they do not understand public and private behaviour and will often behave inappropriately in public. I would like to see XXX develop lifelong skills to keep them safe and enable them to participate and engage fully in their community.



## Appendix 3 - Services and community - Informal and formal supports (example only)

### Informal supports:

- Family: Mum, Dad and siblings

### Community and Mainstream Supports:

- Paediatrician – XXX
- Occupational therapist – XXX
- Speech therapist – XXX
- Swimming teacher – XXX
- Disability support workers – XXX

## Appendix 4 - Current plan (example only)

### Current plan

Our current plan had everything we needed to support XXX to meet their NDIS goals.

or

Our current plan was good, but we had difficulty employing support workers so we could utilise the funding in XXX's NDIS plan.

or

XXX's plan did not have adequate Daily Living – Capacity Supports to meet XXX NDIS goals and demonstrated poor value for money. We relied on our family to provide supports beyond what is expected of a typical XXX year olds family to provide.

## Appendix 5 - Goals (example only)

### **My first goal is:**

For XXX to remain safe and be able to participate fully in home and community life, including developing appropriate behaviours for everyday life.

### **My second goal is:**

For XXX to receive supports required to be able to engage in conversation with a peer for up to 10 minutes.

### **My long-term goals and aspirations are:**

For XXX to build their independence skill in all areas of daily life, including self-care, communication and fine and gross motor skills.

For XXX to learn to keep themselves safe and continue to learn about human development.

**Relates to:** e.g. Life-Long Learning.

## Appendix 6 - Undiagnosed/rare genetic condition short summary (example only)

### XXX Syndrome

The XXX gene is located on chromosome XXX. It is important for the normal development of the embryo before birth and the immune and neurological systems after birth.

It is estimated that there are XXX cases of XXX syndrome in the world with no two people presenting with the same gene change on their XXX gene. People with XXX syndrome have subtle characteristic facial features, and there can also be other congenital malformations and immune system issues. Features and symptoms can include:

- Prominent forehead
- Microcephaly (small head)
- Difficult behaviour (oppositional defiance disorder, ADHD)
- Autism
- Epilepsy
- Intellectual disability
- Movement disorder, e.g. muscle twitching, tremors

Children with a XXX syndrome should be followed by a developmental paediatrician, particularly one who is familiar with children with developmental challenges and the use of medications for behavioural disorders. Children benefit from early intervention supports such as physical therapy, speech therapy, and occupational therapy to maximise their potential.

### **An example of a capacity building support**

#### Support item - occupational therapy sessions

- Frequency - weekly one hour sessions
- Goals - for XXX to independently dress themselves
  - for XXX to use a knife and fork
  - for XXX to wash themselves with prompts in the shower
- Why they are reasonable and necessary - a typical XXX year old can feed, dress and wash themselves
- Refer to the supporting letters from XXX's (current occupational therapist) and XXX's (paediatrician), which include references to recent assessments as evidence that XXX should be working towards these goals and how they will work with them to achieve them.
- Management - NDIS managed