



AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

CARERS GUIDE

PSYCHOSOCIAL DISABILITY AND THE NDIS

MAY 2019

Definition	Carers SA defines a carer as a person providing unpaid care for a parent, partner, child, relative or friend who has a disability, is frail, aged, is dependent on alcohol or other drugs, or has a chronic physical or mental illness.
Disclaimer	<p>While every care has been taken in ensuring that all the information is correct when compiling this resource there may be some omissions and errors.</p> <p>Carers SA does not guarantee outcomes as a result of using this information. This resource is for information purposes only and does not constitute advice.</p> <p>The contents of this entire document cannot be viewed as legal advice and should not be relied upon as such.</p> <p>It is considered a living document and as such it is expected that content will be updated periodically.</p>
Title:	Carers Guide to Psychosocial Disability and the NDIS
Date:	May 2019

Contents

ACKNOWLEDGEMENTS.....	5
INTRODUCTION	6
WHAT IS A PSYCHOSOCIAL DISABILITY?	7
NATIONAL DISABILITY INSURANCE AGENCY (NDIA)	8
WHERE TO START.....	10
The NDIA	10
The Local Area Coordinators in SA (LACs)	10
Where do carers fit into the NDIS?	11
NDIS PATHWAY	12
ACCESS.....	12
Supporting Evidence.....	18
Transport	22
Decision time-frame regarding eligibility.....	24
PREPARE	27
Being prepared	28
Step 1 Additional information.....	28
Step 2 Carer's statement.....	28
Step 3 - Participant statement	31
Step 4 - Goal setting.....	32
Step 5 - Support person	35
Step 6 - Planning options	36
Step 7 - Support coordination.....	39
Step 8 - What to bring to the meeting	41
Questions for the planner.....	42
DEVELOP.....	43
Planning meeting	43
IMPLEMENT.....	46
RECEIVING THE PLAN.....	46
REVIEW	48
RECAP	49
SELF CARE.....	50
BIBLIOGRAPHY	51
USEFUL CONTACTS	52
NDIS GLOSSARY OF TERMS	52

THIS PAGE HAS BEEN DELIBERATELY LEFT BLANK

ACKNOWLEDGEMENTS

The NDIS process is not an easy one and many carers who support people with disability have told us it can be confusing, challenging and daunting. Those carers who successfully navigated the NDIS with, and on behalf of, their family member with disability, said that the reason for this was because they armed themselves with information, went to as many information sessions about the NDIS as they could and sought help from service providers and therapists who they had an established relationship with. Even so, many commented that it was still a difficult process.

A significant number of carers reported that they don't know where to start or can't understand the information they received. Carers regularly voiced that they were unsure where they 'fit' into the NDIS as it seemed to be all about the person with disability yet frequently they are the people who provide the intensive support required to enable their family member to live in the community. They often commented on how they are time poor and are unable to attend NDIS forums. They expressed sorrow and frustration in not being able to help the person they care for because of one, some or all of these factors. This is particularly true for carers of people with psychosocial disability.

In developing the carer's guide we hope to lessen carers' anxiety about the NDIS by demystifying each stage in the process up to and including the planning meeting. Additionally, we hope we can explain the importance of the carer's role in the NDIS environment and what they need to do to ensure their voices are heard.

There are many fantastic websites, publications and documents but often that in itself can be a difficult task in sifting through all the material and finding the resource(s) that are relevant to a carer's circumstances. Also, these resources are frequently focussed on the person with disability. We have aimed to adapt material to help carers understand the NDIS and view the support needed from the perspective of the person with disability while respecting their needs as a carer.

We are immensely grateful to those carers who have shared their NDIS stories with us. Our gratitude also extends to those organisations, individuals and services who have developed resources, which we were able to use or modify for the purpose of the carers booklet. Whenever we have done this, we have acknowledged using their expertise and material and these are listed at the end of this booklet.

Lastly, we wish to thank the carers who took the time to review the Carers Guide. Their insight, comments and advice were invaluable and helped us to craft a resource that remained focussed on the carer through all stages of the NDIS process.

Additionally we have included several websites that carers may find useful. We have also added an extensive glossary at the end of the guide. The glossary may be handy if you are unsure of some of the terms we have used or where we have not explained these fully in the guide.

INTRODUCTION

By now many people in Australia have heard about the National Disability Insurance Scheme. (NDIS). The NDIS commenced in a number of trial sites across Australia in July 2013. Today the NDIS is being rolled out across the country. In South Australia we are told all eligible people with disability will have entered the Scheme by June 2020.

Some people with disability and their families have already had contact with the NDIS. Some have had NDIS plans in place for more than two years and have had these plans reviewed two or three times. Others are still waiting to meet with a Planner and develop their first plan. While others are yet to embark on the NDIS journey.

Whether you and the person you are caring for know a lot about the NDIS or are just getting started, this booklet may be a useful reference guide. It has been developed specifically for people with psychosocial disability and their families and carers, but may also be useful for others with a different disability diagnosis and those that support them.

There is little doubt that people find the NDIS process overwhelming and many carers have voiced their concerns through forums, social and traditional media outlets and at workshops and meetings.

We know there is a lot of information to take in and even this Guide can look a bit daunting.

Tip: The Guide can be used as a reference manual to dip into whenever you want to check something or when you are preparing to start the NDIS pathway

We hope this guide will help explain as clearly as possible the steps in the NDIS journey so you as a carer, and the person you care for, have the information and skills to confidently work through all the NDIS processes.

TESTIMONIAL

"I read the carers guide from cover to cover and then went back to the section I was working through with my son (the preplanning process). It really helped and I knew when we were getting ready for the planning meeting, I could look for the information I needed in that particular part of the guide."

Carer

WHAT IS A PSYCHOSOCIAL DISABILITY?

While you are familiar with the term mental illness you may not have heard the words psychosocial disability before or you are unsure what it means exactly.

Psychosocial disability means that how a person thinks, feels and interacts with other people causes them to have barriers to (or stop them from) fully participating in life.

The term 'psychosocial disability' comes from the United Nations Convention on the Rights of Persons with Disabilities. The convention is important as it is about the human rights of people living with disability.

The word psychosocial refers to the interaction between:

- Psychology – for example a person's way of understanding of their experiences, the world, their emotions and feelings;
- AND
- Social – for example the ways that mental health difficulties are viewed by other people, ways people who experience mental health conditions are viewed by others, or what society and culture define as standard.



Psychosocial disability mostly refers to the social and economic consequences related to a mental health condition. In other words, the person's ability to do things like earn money, buy things they need, have good friends or have a family of their own. It is used to describe the challenges, or limits, a person experiences in life that are related to their mental health condition. It sees these challenges and limits, or impairments, as disabilities that can affect a person's ability to participate fully in life. In NDIS language you will hear such things as 'the impact of a person's illness on their functional capacity'. We will talk about this more fully later in this booklet.

NATIONAL DISABILITY INSURANCE AGENCY (NDIA)

The NDIA is an independent statutory agency that oversees and is responsible for implementing the National Disability Insurance Scheme (NDIS).

The NDIA is responsible for:

- Overseeing the NDIS
- Approving entry into the NDIS
- Approving the funding for the NDIS plan
- Supporting people with disability in remote areas of Australia and about 20% of people with complex needs

What is the NDIS?



Different way of providing disability support

- Available to all eligible people with significant and permanent disability
- Giving choice and control to people with disability
- A shift from funding services to directly allocating funds to the person with permanent and significant disability
- NDIS looks at the functional impact of the disability NOT the diagnosis.

Individualised support

- Funded supports that are tailored to the specific needs of people with disability.

Lifetime Support

- Taking a lifetime approach by investing in people with psychosocial disability early to improve their outcomes later in life.

Focus on impact of disability NOT diagnosis

- Focus is on supporting the person to be as independent as they possibly can be
- Giving choice and control over who, what and where services are provided
- Linking them to the community
- Assisting them to live a meaningful and contributing life

NDIS is not income support

- It is not linked to Centrelink payments, pensions or income earned through a job.
- It is funded by the tax system.
- It is a national program and by 2020 will be available to everyone in Australia who meets the eligibility criteria.

Individual Funding

- The funds are allocated to the person not a service.

WHERE TO START

The people who can help

The NDIA

- Supporting people with disability in remote areas of South Australia.
- Supporting people with disability who have complex needs

The Local Area Coordinators in SA (LACs)

Local Area Coordinators (LACs) are contracted by the NDIA to:

- Assist potential participants through all aspects of the NDIS process including plan implementation.
- Link people with disability and their families and carers to information and support in the community
- Work with the local community to make sure it is welcoming and inclusive of people with disability
- Support all people with disability irrespective of whether they have a NDIS plan or not.

The LACs are a free service that supports all people with disability irrespective of whether they have a NDIS plan or not. Part of their role is to provide you and the person you care for with information and support with community and mainstream services such as health and education.

It is important to remember that LACs cannot approve a NDIS plan. This is the responsibility of the NDIA.

These are organisations that are contracted to provide LAC services in South Australia.

- **Feros Care** - in the Barossa, Light & Lower North, and Northern Adelaide Service Areas: 1300 986 970
- **Baptcare** – in the Western Adelaide, Eastern Adelaide and, Yorke and Mid North Service Areas : 1800 960 595
- **Mission Australia** - in the Limestone Coast, Murray and Mallee, Adelaide Hills, Fleurieu and Kangaroo Island, Southern Adelaide and, Eyre Western and Far North Service Areas: 08 8218 2800

Note: The LACs may initially start the NDIS process with you and the person you care for and then may make the decision that the NDIA is the more appropriate agency to assist you in the NDIS process.

Where do carers fit into the NDIS?

Many families do not identify with the term 'carer' but in NDIS language it is the term used for a family member(s) or friend who provides support to a person with disability. Another term used is 'informal support' which means someone providing support that is unpaid. Carers invariably fall into this category.

The NDIS is focussed on the person with disability yet there is an awareness that carers often play a significant role in their care and support. It is important that a carer informs the NDIA about the extent and intensity of their role in their family member's life and whether it is sustainable.

When talking with many, many carers they have told us that they have been providing many, many hours of support over many, many years.

"It's what we do. We see it as our responsibility and quite frankly there has been no other option. But we won't live forever and we want to make sure there is a plan in place before we either cannot do it any longer or we die. We've never really had a separate life away from our son. We've only had one holiday away from him in 15 years and that was only for four days. Now that he has a NDIS plan we can breathe easier. We are no longer on 24 hour call and we are even planning a holiday"

Carer

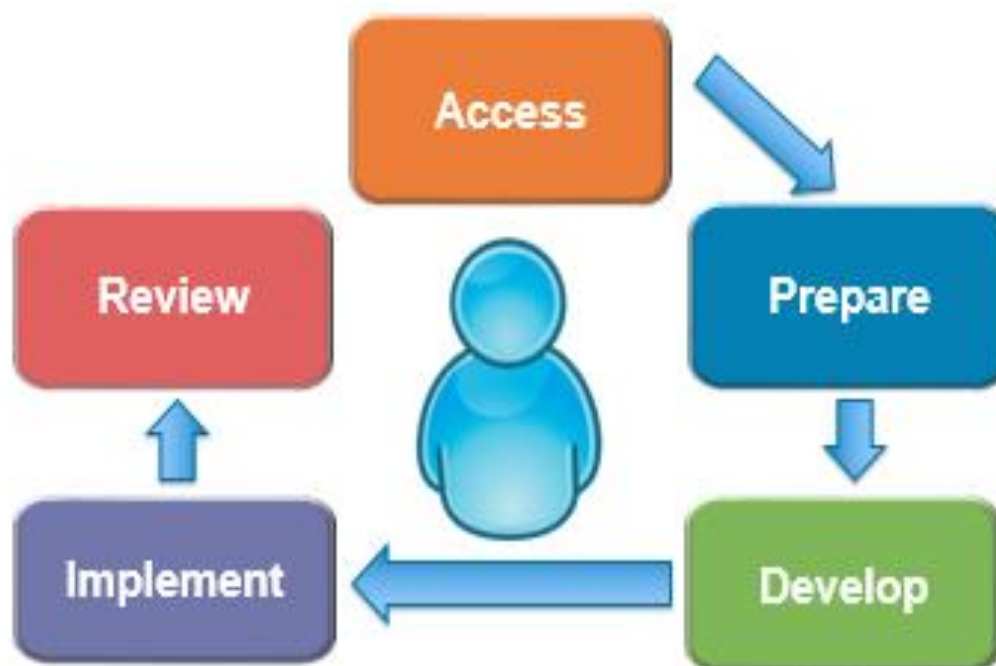
In our conversations with carers they have said that they are hesitant in talking about themselves and their needs because it sounds selfish and could be seen as they want to walk away from their family member. We know that is absolutely the last thing they want to do.

The NDIS is an opportunity to get the right support in place for the person with disability but just as important it allows carers to let go of the reins to some extent and reduce the intensity of their caring role.

The NDIA won't know about the level of a carer's support unless they are told about it. Your views and experiences will be important in the planning process. Therefore it is absolutely essential that you take the time to prepare a carers statement and take it with you to the planning meeting. Later on in this booklet we will explain what could be included in a carer's statement.

Throughout this booklet we will also introduce you to NDIS language and terms. It is useful to know these as you and your family member work through the NDIS steps.

NDIS PATHWAY



This guide will help you understand the **Access** process as well as how to **Prepare** for the planning meeting and what happens when you meet with a planner to **Develop** the plan. It will only lightly touch on the **Implementation** and **Review** processes, with the purpose for you to gain a common understanding of the two final stages.

ACCESS

The first step in the NDIS process is called Access which means you have to check to see whether the person you care for is eligible for the NDIS. Not all people with a mental health condition will be eligible for the NDIS. If the person you care for is receiving support from an existing Commonwealth funded mental health program it is useful to check with them to see whether they have already completed this first step in the access process. They also may have completed the Supporting Evidence Form and they will tell you if they have done so.

All other people with disability will need to connect directly with the NDIA to complete an Access Request Form (ARF) as well as a Supporting Evidence Form.

The ARF will gather the person's details, contact information, information and details regarding any support they receive, both formal and informal, relating to their disability.

There are two different ways you can complete the first part of the Access Request Form on behalf of the person you care for. You can fill out a paper Access Request Form (ARF) or you can make a Verbal Access Request (VAR).

Access Request Form (ARF)

You can get an ARF from your Local Area Coordinator or your local NDIA office or you can call 1800 800 110 and request for the ARF to be sent to you either by email or via post.

If you are filling in an ARF make sure that when you return the form you include written permission from the person you care for to communicate with NDIA on their behalf.

Verbal request form (VRF)

Some people choose to complete the first part of the ARF over the phone. This is the most preferred method as waiting periods regarding response from the NDIA can be reduced. However, make sure that the person you care for is present so that they can give the NDIA verbal authority over the phone for you to talk on their behalf.

Making a phone call to complete the VRF is only the first part of the Access process and will take approximately 20-30 minutes. Make sure you have sufficient time to make the call to the NDIA and that you are not distracted, such as the person you care for requiring your constant attention.

Once you have completed this first stage, the NDIA will then send you the second part of the form which is the Supporting Evidence Form. The NDIA will allocate a 'Unique Identifier' number to the person you care for. This will be given to you over the phone and will also be sent to you along with the Supporting Evidence Form.

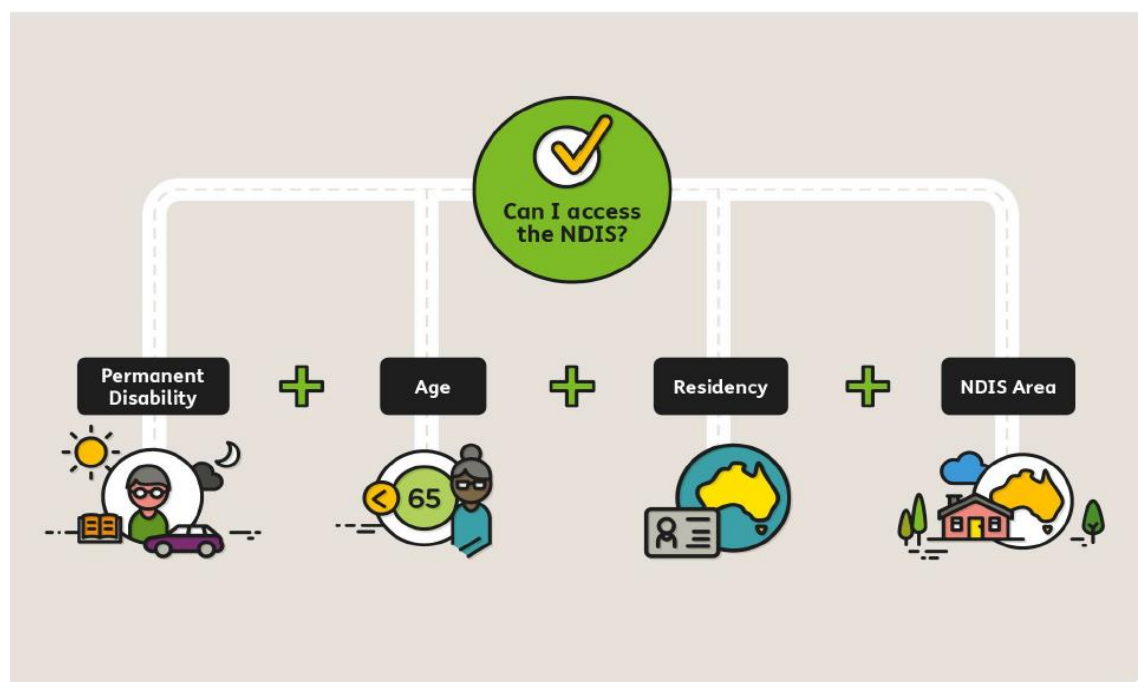
Tip: *The VRF process short circuits the Access Request process as the NDIA receives the details faster and can provide the person's Unique Identifier number over the phone. Any time you speak with a NDIA representation about the person with disability they will ask for this number.*

It is highly recommended that you take advantage of short circuiting the process, because it is a time saver and your request for an ARF doesn't get lost in the system. You can also ask the LAC to help with this process

The Access Checklist questions the NDIA will ask

1. Is the person you care for an Australian resident/citizen?
2. Are they under 65 years old?
3. Do they usually need support from a person or equipment to do everyday things for themselves because of an impairment or condition that is likely to be permanent?
4. Do they need some supports now to reduce their support needs in the future?

Access request proof of identity



The NDIA representative will also ask you for the following information:

- Confirm the person's identity and your authority for you to act on their behalf
- Confirm the person's agreement to enter the NDIS
- Seek permission to gather information about the person from other people including yourself, other family members, current support provider, GP or other health workers
- Determine if the person you care for meets the [NDIS access requirements](#) (this relates to their age, residence, and disability).

Tip If the person you care for has had previous communication or support from Centrelink, you can provide their Centrelink customer reference number (CRN) for proof of identity. This is a faster method instead of providing evidence such as birth certificate, citizenship documents, licences or passport.



Access request, what you need to know

IMPORTANT – things to remember about Access to the NDIS

The disability must have a significant impact on the person's day-to-day life and their ability to participate in the community. That is:

- The severity of the impact on functioning may fluctuate e.g. episodic nature of some conditions such as chronic depression, schizophrenia, bi-polar
- The person you care for will, or is likely to need supports for the rest of their life.

REMEMBER – when thinking about your caring role

When speaking with the NDIA you may be asked a series of functional impact questions – be careful how you answer these!

If you are asked a question about the person's ability to manage to live independently you may be inclined to downplay the level of support you provide. But think what would happen if you were not there to help and were away for say a week. Think what you would tell a neighbour who offered to take your place while you were away. The neighbour may know the person to say hello to but they had never actually provided direct support.

Things you may consider

- What would they need to know about the person's routines, issues, fears and habits?
- What kind of prompts, reminders and other strategies would they need to know about to assist the person with certain aspects of daily life such as showering, food preparation, housework, taking medication or leaving the house?

Many carers have raised concerns about their family member refusing to go through the Access process as they are either being supported by a mental health program or do not see the need to be part of the NDIS.

Many people with psychosocial disability may have difficulty in developing trusting relationships to positively engage with the NDIS. A carer may be the only significant and enduring relationship they have. For people who are in an existing program it is important for the carer to explain to them that unless they check their eligibility they may not have ongoing support into the future. The federal government has made a commitment to those people who have gone through the Access process and have been deemed ineligible by the NDIA that they will receive continuity of support.

Contact details for the NDIA via phone to register your family member's details.

- 1800 800 110 Monday – Friday 8.00 am – 8.00 pm.
- The NDIS Access Checklist tool is a guide for your information only and is not an Access Request to the NDIA. <https://www.ndis.gov.au/ndis-access-checklist>
- If you need help with English, call the NDIA TIS service on 131 450
- If you have hearing or speech loss, call NDIA's TTY service on 1800 555 677. For Speak and Listen, call 1800 555 727.

What is Continuity of Support (CoS)?

- Existing clients of Commonwealth mental health programs who are not eligible will receive CoS
- CoS allows existing clients to be supported to achieve similar outcomes as before, even though the arrangements may be different and may change over time.
- People who chose not to test their eligibility may not receive CoS when funded programs wind down.
- People who are unable to test their eligibility due to an acute episode of their mental health issue or other delays will continue to be support until they are ready to commence their NDIS process

For those who do not want to access the NDIS or who are **denied** access Continuity of Support (CoS) is the alternative option.

Note: CoS: *is not a solution if the person you are caring for refuses to access the NDIS as funding is limited and services may not be able to provide as much support if any as they previously had. Trying to access the NDIS is the better option.*

It is unclear as yet how long CoS funding will be in place for the three federally funded programs. Although the government has made a commitment of it to be ongoing.

CoS Supports are: Partners in Recovery (PIR), Personal Helpers and Mentors (PHaMs) and Day to Day Living (D2DL).

Anyone who currently accesses a Commonwealth disability program who is ineligible for NDIS will continue to receive support through CoS. Continuity of support arrangements will vary for different programs and services. The arrangements for these supports may also change over time.

The National Psychosocial Support (NPS) is a new program which has become available from January 2019 which provides psychosocial support to people with severe mental illness who are:

- currently not receiving any support through a program

AND

- those who currently are receiving support from PIR, D2DL or PHaMs and have not yet tested their NDIS eligibility or are waiting to hear about their, "Access", decision or approved plan for the NDIS

They will be supported for up to 12 months from July 2019 until they have transitioned either to the NDIS or CoS.

Primary Health Networks: (PHNs) will commission service providers in local areas to deliver these psychosocial supports. It is expected that many people will stay with their current service provider.

Better Access Initiative

The Better Access initiative is available anyone with an assessed mental disorder who would benefit from a structured approach to the management of their treatment needs.

What Medicare services can be provided under the Better Access initiative?

Medicare rebates maybe available for up to ten individual and ten group allied mental health services per calendar year to patients with an assessed mental disorder who are referred by:

- A GP managing a patient under a GP Mental Health Treatment Plan
- Under a referred psychiatrist assessment and management plan
- A psychiatrist or paediatrician

Mental health services under this initiative include psychological assessment and therapy services provided by clinical psychologists, and focussed psychological strategies services provided by appropriately qualified GPs and eligible psychologists, social workers and occupational therapists.

Psychiatrists and paediatricians are able to directly refer someone with mental disorders for Medicare rebateable allied mental health services.

Health Professionals are free to determine their own fees for the professional services they provide. Charges in excess of the Medicare rebate are the responsibility of the person.

Guardianship

If the person you care for is unable to make reasonable judgements because of their disability and there are concerns about the decisions they are making you may need to consider guardianship. However guardianship is a last resort and only used if there is no other less restrictive alternatives that takes the person's rights into consideration.

For more information you can contact the:

Office of the Public Advocate

www.opa.sa.gov.au

- Telephone: 83428200 or for country caller 1800 066 969
- TTY users phone 133 677 then ask for 08 8342 8200
- Speak and Listen users phone 1300 555 727 then ask for 08 8342 8200
- Internet relay users connect to the NRS <https://internet-relay.nrscall.gov.au> then ask for 08 8342 8200

Supporting Evidence

This is the second part of the ARF. It provides the NDIA the evidence relating to the person's psychosocial disability and their need for lifetime support.

Once you and/or the person you care for receives the second part of the ARF, which refers to providing supporting evidence, you will need to complete and return the information within 28 day. However you can contact NDIA and request for an extension for another 28 days if you are still gathering evidence. After that time if there is still a delay in collecting all the required evidence it is important that you contact the NDIA and inform them as soon as possible to discuss why you are seeking a further extension.

TIP Collecting supporting evidence should commence as early as possible and can happen well before you begin the Access process. It often takes time to get the right reports, make appointments with the GP and or psychiatrist, or psychologist or allied health professional or a service provider.

It is important that the evidence is as recent, less than one-year-old, if possible.

Evidence based reports are critical essentials in assisting the NDIA to determining whether the person will receive a NDIS funded package and how much funding will be granted. The reports must detail the functional impairment not just the disability diagnosis.

Regarding what is needed

Adding recommendations into any report will explain to the NDIA exactly what supports the person will need included in their plan.

Functional assessments outline the challenges and impact of a person's mental health condition on their daily functioning. Some examples of functional assessment that professional may suggest or use are:

- World Health Organisation Disability Assessment Scale (WHODAS 2)
- Life Skills Profile (LSP-16 or 32)
- Health of the Nation Outcome Scale (HoNOS)
- Living in the Community Questionnaire (LCQ)+-
- Camberwell Assessment of Need (CAN or CANSAS)
- Recovery Assessment Scale – Domains and Stages (RAS-DS).

Some assessments may be partly funded under the Medicare rebate scheme or Better Access initiative.

If the person you care for does not have recent existing evidence they will need to have an assessment completed. A suitably trained health professional can undertake an assessment. ('Health professional' includes a physiotherapist, an occupational therapist, speech pathologist, psychologist or a suitably qualified nurse).

Evidence could be in the form of existing information that you already have about the person such as;

- any difficulties the person may have in leaving the house
- concerns about social isolation and/or lack of activities
- any difficulties the person may have in getting to know new people
- difficulties in particular environments or particular sensitivities, fears or trigger situations
- difficulties in adapting to change, or a need for slow, supported approach to new experiences
- risks to the person's safety and wellbeing if family could not sustain their role and assist anymore
- Supporting letters from support providers the person is connected with
- Assessments or other reports from a health professional example; GP, psychiatrist, psychologist or occupational therapist
- Information about hospitalisations and treatments

A person's GP is often a critical person to provide supporting evidence as they generally see the person on a regular basis.

You may also include a carer statement but it is not essential for this to be sent with the supporting evidence. It may be brought to the planning meeting. Even if you have sent it with the person's information it is useful also to bring it to the planning meeting.

TIP Make sure you book a double appointment with the GP and bring additional information to assist the doctor to provide sufficient information to the NDIA. Some carers have prepared a draft of what information should be provided to help the GP understand the process.

Many GPs are not aware of the supports a person may be currently receiving or what the NDIS can provide. If there are other reports already completed by other professionals it can be useful to show these to the GP to show the impact of the psychosocial disability on the person's daily living.

There is also a fact sheet available for GPs on the NDIS website called 'A GP guide to the NDIS' which is also helpful.

<https://www.ndis.gov.au/applying-access-ndis/how-apply/information-gps-and-health-professionals>

If the person you care for sees a psychiatrist on a regular basis a request for a supporting letter is also very helpful.

You can provide the evidence by having their treating doctor or specialist complete the Professional's Report section (Part F) of the Access Request Form. It is not essential for this form to be used as long as any documents or letters you provide address the requirements set out in Part F.

TIP A diagnosis is not essential to access the NDIS although it is extremely helpful if it is available. The NDIA requires confirmation that the mental health condition results in substantially reduced functional impairment that treatment will not remedy.

The evidence needs to provide details on:

- The mental health condition/ psychosocial disability
- Evidence of any treatments that the person has had, is currently receiving and treatment options which may be considered in the future.
- How long the mental health condition/psychosocial disability will last (remember that to meet the access requirements it needs to be likely that the condition will be permanent and lifelong)
- The disability results in substantially reduced functional capacity and
- How it impacts on both the person you care for and you the carer on a day-to-day basis

The more information you provide to the NDIA the better able they are to make a decision about the person's eligibility.

TIP Remember to keep copies of all and any information you send to the NDIA.

Note: *The NDIS is designed to complement existing community services and is not a replacement for clinical services, mental health case management or medical care.*

Function Impairment and the NDIS

NDIS rates functional impairment on how a person's psychosocial disability affects their daily activities in areas of, self-care, self-management, social interaction, learning, mobility and communication.

The first three known as the **3xS** are viewed by the NDIA as significant criteria when assessing a person's eligibility.

When speaking to people who are developing supporting evidence documentation make sure they address one or more of these areas and describe how they affect the person's life, for example;

Core Requirement – focus on (minimum one of) 3xS

- **Self-care** – how a person manages things such as their diet, exercise, personal grooming, medication or sexual health or does it result in self-harming
- **Self-management** – a person's ability to manage personal finances, maintain their accommodation (tenancy) Also if the disability impacts on the person's motivation, interest in life or ability to concentrate or prioritise tasks
- **Social interaction** – the person's difficulty with social interactions and maintaining relationships with family, peers or at work

PLUS:

- **Learning** – is there an impact on the person's planning, memory concentration or ability to learn new information or participate in group learning?
- **Mobility** – does the person have difficulty in leaving the house, use public transport, go to shopping centres or attend recreational or vocational activities or experience mobility issues such as tremors as a side effect of their medication?
- **Communication** – does the person have difficulty in initiating or maintaining a conversation, communicating their needs and wants, or following instructions, conversations or directions?

Note: People with psychosocial disability can have fluctuating or episodic periods of their mental health condition which severely limits their ability to function. The NDIA will consider how a person is able to function in between these acute episodes. If they are able to live a fairly reasonable life in between these episodes then they are less likely to meet the access criteria of substantially reduced capacity.

Transport



A word about transport

Some people with psychosocial disability are receiving a Mobility Allowance. You need to be aware that for those people who are found to be eligible for the NDIS that this payment will cease once their plan is approved.

It is therefore important to consider transport when preparing for the planning meeting both for those people who are currently receiving a Mobility Allowance as well as those that don't but would benefit in having a travel budget in their NDIS plan.

Transport related supports which may be funded by the NDIS may include:

- Personal transport related aids and equipment
- Training to use public transport independently
- Reasonable and necessary taxi or private transport costs if the person is unable to use public transport independently

Note: *The NDIS will not fund transport supports due to lack of availability of public transport. Things to consider about transport before the planning meeting:*

- *Think about how the person you care for uses transport to travel to appointments, social activities – would they be able to attend these if you as the carer didn't provide the transport*
- *If there was appropriate alternative transport would the person you care for use it and what sort of additional support would they require?*
- *Would it make a difference in their life and yours?*

How much NDIS transport is available?

There are three levels of transport funding that will be paid fortnightly in advance into a nominated bank account. It can include the cost of public transport, taxi fares and/or covering a support worker's mileage if they are using their own vehicle to transport the participant.

- **Level 1:** Up to \$1,606 per year for participants who are not working, studying or attending day programs but are seeking to enhance their community access.
- **Level 2:** Up to \$2,472 per year for participants who are currently working or studying part-time (up to 15 hours week), participating in day programs and for other social, recreational or leisure activities.
- **Level 3:** Up to \$3,456 per year for participants who are currently working, looking for work, or studying at least 15 hours a week, and are unable to use public transport because of their disability.

TIP: Don't forget to record how the person you care for gets to activities. Often people forget to mention that the person catches a taxi to get to some of their activities or currently receiving a mobility allowance.

This allowance will be included into the NDIS plan so it is important to mention this to the planner.

South Australian Transport Subsidy Scheme (SATSS)

Note: While the National Disability Insurance Agency further refines its transport policy, current SATSS members who have transitioned to the NDIS will be issued **one further book of 80 SATSS vouchers when they re-order voucher books before 30 June 2019** (in accordance with the conditions of the SATSS).

SATSS members who have transitioned to the NDIS and receive **Journey to Work vouchers**, should contact SATSS administration on 1300 360 840.

If your person does not transition to the NDIS or is waiting **a plan nothing will change and new voucher books can be re-ordered** through SATSS **as usual** (in accordance with the conditions of the SATSS).

If you have any questions, the SATSS information line can be contacted on 1300 360 840.

For more detail regarding Transport and the NDIS:

<https://www.ndis.gov.au/participants/creating-your-plan/plan-budget-and-rules/transport-funding>

Decision time-frame regarding eligibility

The NDIA should let you know their decision within 21 days of the application being 'lodged' and they are satisfied that they have all the information they require to make a decision around eligibility. It may take longer than 21 days if there have been further request(s) for more information. The 21 days is only relevant once the NDIA is satisfied that they have received all documentation.

If there is a delay in assessing the person's NDIS application for any reason, the NDIA should make contact to advise why there is a delay. According to some carers this sometimes doesn't happen so if there is no communication from the NDIA within 21 days after all information has been lodged, you should follow up for an update and to ensure there are no problems. Perseverance is vital.

TIP: whenever you have a telephone conversation with a NDIA representative ask for a reference number so you have a record of the phone call and write yourself a note about what the call was about.

Make sure the person you care for has given both verbal (during the VRF process) and written consent to act on their behalf. This should include both consent to allow you to speak on the person's behalf and to sending and receiving all copies of written communication. If this does not occur the person will receive all paper work and phone calls and you may be left unaware of any decisions made regarding anything relating to them and the NDIS.

The NDIA use the term nominee when the person with disability gives permission for a carer (or another) to act with and on their behalf. There are two types of nominees:

- A correspondence nominee who can undertake most activities on behalf of the person **except** preparing or making changes to a plan and managing the funds
- A plan nominee who can undertake all activities on behalf of the person but certain activities can be limited if appropriate.

If you have Guardianship or Power of Attorney make sure you tell your LAC or NDIA representative as the NDIA will take this into account during the Access process.

The NDIA will take into consideration the views of the appointed guardian as you are able to make decisions on behalf of the person you care for.

The NDIA will request legal documentation relative to Guardianship orders or Power of Attorney.

Decision notification

Once the NDIA has made a decision they should inform you both by a phone call and a letter.

The NDIA's decision will be one of the following:

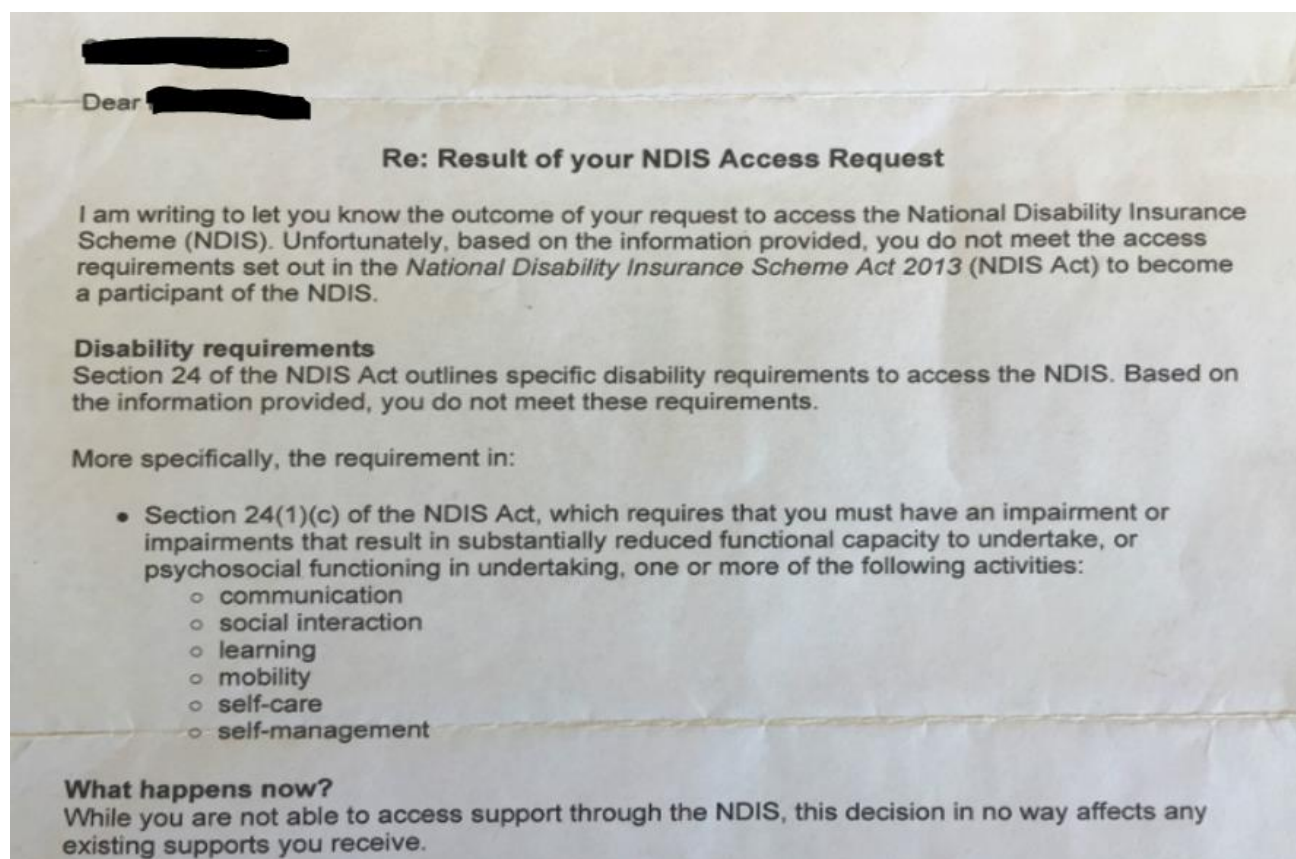
1. The person is eligible and has met the 'disability requirements'
- OR
2. The person is not eligible for the NDIS.

If the NDIA has found the person is not eligible, they should provide information explaining their decision. If you do not understand the decision, it is recommended to ask for more information. It is helpful to ask for this both verbally and in writing. An example for the decision could be due to an inadequate amount of supporting evidence. This is why it is so important to clarify why the person was found to be ineligible for the NDIS.

The NDIS letter will also tell you how to request a review if you do not agree with the NDIA's decision. You will need to make this review request within three months of being notified of the decision. If you do not do this within three months you can reapply but you will need to make a new access request.

TIP: Due to long waiting periods for review carers have reported that it is faster to wait a month then reapply including additional information with clarification of evidence of the person's functional impairment.

Example NDIS declined Access letter:



The letter does not pinpoint exactly why the Access request was denied. It is worth repeating that this is why it is so important to clarify why the person was found to be ineligible for the NDIS..

TIP: It is part of the LAC's role to assist people with disability and their carers with the Access process, make sure you make contact and follow up with them if your Access request was denied so they can help you moving forward.

PREPARE

Pre-planning

Carers have told us that the pre-planning step was probably the most important step once Access was approved. Some carers had used specific workbooks for people with disability that service providers had developed, others checked out various websites including the NDIS website to get more information, some had attended specific workshops, while others had friends who had gone through the NDIS process and provided first-hand information and advice. Social media was also mentioned as well as linkages to support groups and newsletters.

Being well prepared made all the difference. I knew what to ask for at the planning meeting. I understood most of the NDIS language and my daughter and I had a support person (family friend) go with us to the meeting. I had lots of conversations with my daughter about what she would like to do even though this was really hard as she really doesn't want to do anything and doesn't like new people in her life. I didn't want to put words into her mouth or make decisions for her but I know what she needs and I can't keep doing it all."

Carer

Being prepared meant that when these carers went to the planning meeting they had:

1. Any **additional information** they believed was useful
2. Prepared a **carer's statement** including whether there were any events in the next 12 months that reduced their capacity to provide support
3. Supported their family member develop a **participant statement** which included their goals for the next 12 months
4. **Set goals** – be S M A R T
5. Chosen a **support person** to come with them
6. Knew about **planning options**
7. Knew about **support coordination**
8. Knew **what to bring to the meeting and had a list of questions for the planner**

Being prepared

Where to start if you do not have access to some of the things carers have mentioned?

There are many workbooks that can help including those on the NDIS website. You can contact the NDIA or the LAC in your area to send you copies of these.

Step 1 Additional information

You may have spoken to other people who have been involved in the person's life who have given you a report or letter that was not included in the Supporting Evidence documentation. This could be a worker who has or does provide support to the person or a treating doctor or allied health care professional who was unable to provide information at the time the documentation was sent to the NDIA.

Step 2 Carer's statement

You have the option of including a carer statement when you send in the supporting evidence or bring it with you to the planning meeting. Even if you have sent it is worth bringing it along with you. Some carers have said it was difficult to speak about all the issues with their family member present as it could sound very negative and upset the person. You can ask to extend the meeting without the person you care for being present or ask for a separate meeting to discuss more fully your concerns if you want to.

Each family member can write their own carer statement including siblings and extended family members. This information will assist the NDIA to better understand the nature of the supports required in the person's daily life and why they are necessary.

These additional pieces of information have greater relevance if say a sibling has been providing support every weekend but is now moving elsewhere and is unable to maintain the contact.

When developing in carer statement it is useful to think about:

- How the caring role affects you
- Whether you are able or willing to keep caring for the person with disability in the same way
- Whether your family member with disability is aware of the extent of the support you provide

- Consider whether it is appropriate for you to assist the person you care for in a particular task, or would it provide greater dignity, choice and control for the person to receive help in this situation from someone else.
- How many hours of support you provide on a daily/weekly basis and whether this is sustainable
- The impact of the caring role has on your family relationships and other social networks and on your own wellbeing and health
- What other family, friends and community networks to person may have and whether these have deteriorated over time
- Whether there are events or issues that are coming up in the next 12 months that will impact on your caring role such as planned hospitalisation, going away for a period of time or increased caring responsibilities for other family members



TIP: It is very difficult to remember everything you may do in your caring role on a daily basis. Having a little note book close by and quickly jot down all the things you do for the person you care (as soon as you do it if possible). The information is very helpful to refer back to when writing your carer statement.

Examples of these may include taking phone calls from the person 20 times a day, being always on call, making sure that any important letters are not lost or thrown away and consequent results such as utility bills being unpaid and power being cut off, ensuring medical appointments are kept, etc.

It is important to consider past crises and what would happen if you were not there to help manage these, such as when the person's mental illness suddenly becomes worse. The NDIA is not a crisis management service so having a contingency plan within the NDIS plan is worth considering

Tandem website has a template that you can help write your Carers Statement: <https://www.tandemcarers.org.au/gathering-evidence.php>

Click on to website, scroll down to NDIS tools and click on to '**Carers Statement**' and allow, this will open up a word document that you can edit and print.

How does NDIS support carers and what will it pay for?

The NDIS knows that unpaid families and carers are critical to the support and wellbeing of people with disability and recognises that their support load, illness and ageing can place carers' wellbeing at risk and compromise their capacity to continue in the caring role.

Supports for Sustaining Informal Support are a range of supports in a person's NDIS plan that assist in sustaining a caring relationship between the person with disability and their families and carers.

Example of this kind of support includes:

- Family support and counselling due to a family members' disability.
- Building the skills and capacity of other family members to manage the impact of a participant's disability on family life.
- Supports that increase the participant's independence, as well as supports that enable the participant to enjoy social and community activities independent of their informal carers.
- Supports aimed at increasing the sustainability of the family caring arrangement, including support with personal care and domestic assistance related to the person's disability.
- Requesting a support worker to be included in family outings to provide assistance and guidance for the person with disability, especially where the family has other children to supervise and engage with. This allows for the person with disability to be included in family events and outings and provides opportunity for social participation.



Step 3 - Participant statement

Preplanning is an opportunity to look at what are the current circumstances in a person's life, the level of support that is being provided (including your input), identifying any gaps and to think about things that could be achieved with the right support in place.

All these things help to develop a formal participant statement at the planning meeting.

So what does the planner want to know?

- Where the person lives and who they live with
- Important people in their life and the role they play
- Things they are good at and what they enjoy
- Things that are important to them
- What's working and what's not and what they would like to change
- Their goals and hopes and dreams – the last two are called aspirations in NDIS speak
- Who the person would like to be involved once a NDIS plan is in place

TIP: It is useful to have a copy of two weekly planners. The first describes what a person's life looks like now and the second what an ideal week would look like.

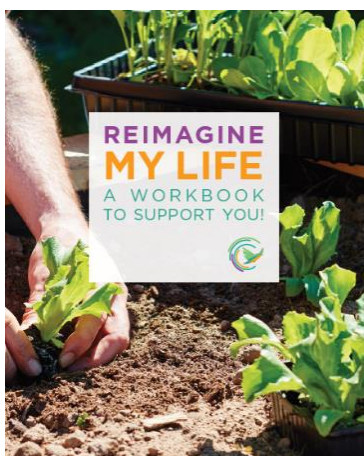
There are many work books that can help you through this process; for example, the ones on the reimagine or NDIS websites

Reimagine

<https://mhcc.learningcart.com/uploads/Reimagine/Reimagine-workbook.pdf>

NDIS workbook 2 planning

<https://www.ndis.gov.au/about-us/publications/booklets-and-factsheets#participant-booklets>



Step 4 - Goal setting

Goals are all about what a person want to achieve and the steps that need to be taken to achieve these. The NDIS is very goal focussed.

When thinking about the goals in the NDIS environment it is also important to understand what is termed ***Reasonable and Necessary Supports***

Reasonable and necessary

The NDIS only funds support that is deemed 'reasonable and necessary' which is defined under six criteria in Section 34 of the NDIS Act.

Funding for any type of support will only be approved if is related to the person's disability and meet all six criteria which are:

1. Goal related
2. Assist with social and economic participation
3. Value for money
4. Effective and helpful
5. Not more appropriately provided by family or the wider community
6. Not more appropriately funded by other service system (e.g. health, education, justice)

TIP: The planner will consider what support is currently being provided by the "informal networks" such as by you the carer (that is why a carer statement is absolutely essential), and the community as well as any mainstream services.

Do not assume the planner fully understands your needs and those of the person you care for. Be prepared to talk about why a support request is fair and reasonable.

Goals and NDIS criteria

- All NDIS plans start with goals, or a vision of the future for the participant.
- Clear goals for a positive future are a good start to setting some shorter-term goals for the next 12 months.
- As a carer you can start by talking to the person about developing their goal and what supports are needed to achieve them.

Example Goal:

The person I care for needs support to maintain a positive and hygienic home environment

Goal: To independently look after myself and my home (the person with disability)

When looking at support needs, think carefully about all the supports the person you care for needs – from the time they wake up, where they spend their day and what they like to do in the evenings.

Ask: “What supports does the person need for their everyday activities?”

TIP: It can be difficult highlighting the challenges that the person is facing but it is essential and remember you won't get anywhere with painting a rosy picture.

As a carer you need to record:

“ ... not what the person can do, but what they [actually] ‘do’ do...”
Sam Paior
Carer and Consultant

When developing goals, aim to develop SMART goals:



SPECIFIC - MEASURABLE - ATTAINABLE - RELEVANT - TIME BASED

Things to consider when creating goals:

- What supports does the person already have in place?
- If something is stopping the person from achieving their goals?
- What steps may the person need to take to get where they want to be?

Q. What might be some examples of goals for the person you care for?

- building skills to get ready for joining a community activity
- developing communication skills to express themselves
- developing social skills to make friends.

You should be prepared to identify exactly what the person you care for needs in order to work towards their goals. All the support required will need to be detailed at the planning meeting.



Think about things such as:

- The support required
- A contingency plan when things go pear-shape
- Any equipment needed
- Behaviour support requirements
- Travel and transport requirements
- Home or vehicle modifications
- Support coordination (more on this later)

Example of what a participants NDIS goals will look like once a plan is completed



Part 2: My goals

This part of my Participant Statement lists the goals I want to work towards during this plan.

My First Goal is:

During this plan: I would like to increase my overnight stays to enhance my independence and decrease my dependence on my family with the goal of living in supported accommodation in the future

My Second Goal is:

During this plan: I would like to learn strategies to help me manage my emotions and anger and improve relationships with family members and allow me to increase my inclusion in community activities.

My longer term goals and aspirations are:

Goal: I would like to increase my participation in physical activities to assist in maintaining my health and wellbeing.

Relates to: Health and wellbeing

Goal: I would like support to sustain my informal supports

Relates to: Relationships

Goal: I would like a behaviour plan prepared to ensure consistent support with behaviour management across service providers.

Relates to: Relationships

Goal: I would like support to ensure I am able to finish my education.

Relates to: Learning

Goal: I would like support to increase my community participation and social interaction.

Relates to: Social and community activities

Step 5 - Support person

Planning meetings can be events that you and the person your care for have not experienced before. It is very useful and comforting having a support person (or as many as you want) present at a planning meeting. It can be anyone you both feel comfortable with and trust such as another member of the family or a friend, a professional you have an existing relationship or a member from a support group who is knowledgeable about the NDIS.

It is equally important that both you and the support person have worked out the ground rules for the meeting and discuss these before the meeting (not just as the meeting is to take place)

- Share with each support person how much you want them to know and this may depend how well you know the person and how well they know the person with disability and both your circumstances
- Make sure that you and person you care for set ground rules regarding the support person's role before you attend the plan meeting. For example you may want the person to be there for moral support, explain a particular report they have submitted, stay in the background, act as a prompt when needed if something is forgotten or speak when things become challenging.
- You may allocate the person as the minute taker at the meeting. Taking minutes is helpful as it is often hard to remember everything that is said at the meeting. It's also a good check when you eventually get the plan. Matching what you talked about and what's in the plan is always useful.
- If the person with disability becomes upset or agitated what steps can a support person take? Do they encourage the person to leave the meeting for a little while and return later or do they stay with them if they refuse to return to the meeting?



Step 6 - Planning options

During the planning meeting the person you care for (and you) will be asked how you would like the funding in the plan to be managed. You should decide on which option you want before the planning meeting.

There are four different ways to manage the funding in a NDIS plan.

1. NDIA managed (sometimes called Agency managed) will pay the support providers for you.

You still have choice and control over who you choose but this is limited to those provided registered with the NDIA and must follow the NDIA set price guide.

The NDIS Price Guide is reviewed annually and informs you the most you can pay for their services

<https://www.ndis.gov.au/providers/price-guides-and-information#price-guide-for-ndis-providers-as-of-1-february-2019>

2. Self-managed means you will pay the service providers

You have choice and control but also you can choose providers who are not registered with the NDIA, have a service agreement with each provider and tell them how they will be paid, make payment requests and pay for services on time. You also should have a separate bank account for the funds, keep records of payments and keep these for five years.

For resources and practical information about self-managing supports you can go to: www.selfmanagementsupports.org.au

3. A combination of Agency-managed and Self-managed

There may be parts of the plan you want to self-manage, e.g. in the plan there may be an amount set aside for house cleaning and garden maintenance work and you already use a service that you know is not NDIA registered. In order to keep on using that service you will need to self-manage that part of the plan.

Another example may be that the person you care for has a long standing relationship with a therapist. It is important that you check with the therapist whether they are registered. If they are not and you choose the Agency-managed option for the whole plan you will not be able pay for this service with the NDIS funds.

4. Plan Management where a Plan Manager pays providers

The Plan Manager must be registered with the NDIA but the support services do not have to be registered providers.

The Plan Manager has to use the NDIS set price guide to pay service providers.

If you select the Plan Management option an extra amount is included in the plan budget to be used for this purpose.

Plan management can be viewed as all the good bits about self-management without having to worry about budgeting, record keeping and paperwork.

Note: *A number of carers told us that they chose the Agency managed option in their family member's plan for the first plan. As they became more confident and knowledgeable about the NDIS they chose either a combination of 2 through to 4 or decided to entirely self-manage.*

IMPORTANT

If you are using unregistered providers (this includes not just support staff but **anyone** such as gardeners, house cleaners) who are paid with NDIS funds the **NDIS Quality and Safeguards Commission** requires them:

- To comply with the NDIS Code of Conduct
- And
- Be aware of NDIS Complaints policy and processes

The Commission is an independent organisation established to improve quality and safety of NDIS supports and services

For more information about these as well as the NDIS Quality and Safeguards Commission visit: www.ndiscommission.gov.au or contact on 1800 035 544

Step 7 - Support coordination

Support coordination is a support that helps people to activate and coordinate all the supports that they might need including NDIS funded supports, as well as informal, mainstream, community and other supports.

There are three types of support coordination

1. **Support Connection** - Local Area Coordinator's role
2. **Support Coordination** – The most commonly funded
3. **Specialist Support Coordination** – Similar to support coordination but is allocated to participants who have additional or high complex needs and the Support Coordinator will be an experienced allied health professional such as an occupational therapist, psychologist or social worker.

Support Connection

This is the role of the LACs in your area, *Refer to page 11 of the Guide for more details regarding LAC*

Support Coordination

Support coordination begins when a plan is started. A Support Coordinator will help you to understand and use the NDIS plan and link the person (now known as the participant) into community, mainstream and other government services. A Support Coordinator's role is to set up services in a person's plan, monitor and strengthen those services over time and support the person to prepare for plan reviews. The Support Coordinator will also help the participant and the carer to talk with service providers about what they can offer and how much it will cost and make sure service agreements and bookings are completed.

Specialist Support Coordination

This is a high level of Support Coordination and is for those people whose situations are more complex and who specialist need support.

A specialist Support Coordinator will assist the person to manage challenges in the support environment and ensure consistent delivery of services.

Role of the Support coordinator or Specialist Support Coordinator

- Understand the NDIS plan, the NDIS price guide and how to use the budgets in the plan
- Decide what type of supports to purchase and how much of each
- Understand what services you can access that are not funded by the NDIS
- Support you both to talk about what you want and don't want from services
- Help choose NDIS registered service providers
- Help understand and develop service agreements
- Help prepare for NDIS plan reviews
- Help with supporting decision making

Note: *Support coordination or Specialist Support Coordination is not automatically included in a NDIS plan. It is highly recommended that you request support coordination in the person's plan AND when support coordination is included in a participant's plan it will be as a specific budget allocation in the Capacity Building section of the plan.*

This is what it will look like in a plan if support coordination is included – you will find it under Capacity Building

Support Area:	Support coordination
Budget:	\$566.10
Details:	Support Connection assistance to strengthen you and your family's ability to coordinate and implement supports and coordinate a range of community, funded and mainstream supports.
How will the supports be paid:	NDIS will pay my support provider directly for these supports

Step 8 - What to bring to the meeting

- ✓ Identification verification
- ✓ any letters from the NDIA
- ✓ any additional reports you have received
- ✓ participant booklet (if used) and/or participant statement which includes the person's goals
- ✓ carer's statement
- ✓ bank account details if you are considering self-managing some or all of the NDIS plan
- ✓ the person's myGov login and password details (if you need help in setting up the account speak with your LAC or NDIA planner).



TIP: We have found that people who are well prepared for their planning meeting increased their chances of getting the NDIS funding they need. This includes being able to discuss in details what supports they need to help sustain their informal supports –Which is NDIS speak for the important people in their lives who give them day-to-day support.

Most carers are familiar with the term respite and have used it when there has been a need to do so. It's not a word that the NDIA likes so it is useful to use terms such as 'additional in-home support' and short term accommodation' when speaking about respite.

Questions for the planner

Note: you have the right to ask questions, here are some example of questions you may like to ask



1. How will the plan be sent?
2. Is a computer or email address necessary?
3. Can the planner be contacted after the meeting if additional information needs to be provided? i.e. an assessment from an occupational therapist. Ask for contact details of the planner
4. How long after the planning meeting will the plan be sent out?
5. What if something is missing from the plan? What is the appeal process if the plan or part of the plan does not meet expectations?
6. Who will help us to understand the plan?
7. Can we request support coordination and how will it be funded?
8. Can we discuss how the funding in the plan will be managed?
9. Once the plan is received, how long do we have to make a decision about who will provide the support (s)?
10. When does the plan officially start?
11. Where can we find a list of services providers including support coordinators and plan managers
12. Request that a hard copy of the plan is mailed/sent out to you as well as the participant.

DEVELOP

Planning meeting

The person you care for and you will be notified by the LAC or the NDIA about the planning meeting.

You both can tell them:

What type of meeting you would like - either as a face-to-face meeting or over the phone

Where the meeting is to take place – either at home or at a NDIA or LAC office or a place of your choosing

A preferred time of the meeting – morning, afternoon or evening (Monday to Friday)

That you will have a support person(s) at the meeting (it can be more than one)

Whether the person you care for needs any communication aids for the meeting

Whether a translator is needed

Almost always the person you care for will also attend the planning meeting, because the plan is about them. However this may be determined by how well the person is at the time of the meeting. It may be only for a short period of time or for the whole meeting.

If the person is unable to attend the meeting due to some crisis / issue before the meeting another meeting will need to be scheduled.

There is a possibility that the information regarding the person's disability and the effects of that disability on their life and those around them, could potentially be distressing for that person. If that is the case then it may be advisable to ask for a separate meeting or to extend the meeting (without the person present) to discuss more fully issues related to the person e.g. complex behaviours.

However it is useful for the planner to meet the person with disability and to gain an insight into their needs, either through conversation or the person's own communication methods.

TIP: It is worth taking the time to look at the NDIS price guide, this will help when trying to budget the hours and services that will be needed in the plan.

<https://www.ndis.gov.au/providers/price-guides-and-information#price-guide-for-ndis-providers-as-of-1-february-2019>

At the planning meeting

The planning meeting is usually between 1-2 hours in length

The planner will work through a set check-list of questions (some may not be relevant to the person's situation). The questions will be about a participant's functional capacity. This gives the NDIA guidance as to how much support the participant may need over the next 12 months.

The person will be asked about their everyday activities, for example:

- What work they do (if any) both in paid employment and on a voluntary basis?
- How they manage their personal hygiene and self-care and whether they need help and how often?
- What do they do when someone comes to help them at home?
- How involved are they in shopping and cooking activities?
- What links and interactions do they have in community/recreational activities?

The planner will work with the participant and you to determine what supports and services will assist the person to achieve their goals.

Note: *This is where any goal setting pre-planning will prove to be very useful.*

The planner will also consider the role of informal support (generally that's you and your family), explore how mainstream services and community options can assist the person achieve their goals.

TIP: If you are unsure about what the planner is asking, do not be afraid to ask them to repeat the question or statement. The planner will record the answers you give in their **own** words. It is helpful to ask the planner to repeat back your answers to see if they have understood and emphasised the information you feel is important. It gives you a chance to correct any errors or misunderstanding.

Ask the planner at the end of the planning meeting to again read out what has been written. You can also ask for a copy of the document before it is submitted to the NDIA although any such decision will be at the discretion of the planner.

Note: After the planning meeting the planner will take the information provided and forward it to a NDIA Delegate. The Delegate is someone from the NDIA who writes up the plan based on what was discussed at the meeting.

NDIS plans are about the participant's goals and expected outcome and the funding that is allocated to relevant supports that contribute to achieving them.

The participant's first plan is considered to be the beginning of a personal lifelong relationship with the NDIA. The NDIA will continue to work with the participant (and their carers) to review and update their plan as the person's needs change over their lifetime.



We will only touch very lightly on Steps Four and Five of the NDIS process – remember your LAC's will be able to help you through these steps.

IMPLEMENT

RECEIVING THE PLAN

Make sure you have the **right plan:**

- Check the person's (now known as the participant) name and correct spelling and date of birth
- Read over the plan and check the notes you took at the planning meeting against the plan
- As the plan can look quite complex, check that you understand all parts of the plan and if not ask for help from the NDIA, Support Coordinator or the LAC about anything in the plan that is unclear

In your information pack there will be:

- The getting started checklist
- The NDIS plan – which will have the start and review dates
- Budget information
- How the supports will be paid
- Support coordination and/or plan management (if this has been approved)

Once the person you care for has had their plan approved, now you are ready for the next steps. But before you start some important things to know:

1. Activating the plan

Plans do **not** have to be approved by either the participant or carer for them to be activated. You will also receive in the mail an individual 'Activation code' which is connected to the person with the disability.

2. Read and understand the plan

Read and understand the supports in the NDIS plan.

A NDIS plan may have three support budgets:

- Core Supports budget
- Capacity Building Supports budget
- Capital Supports budget

The participant will receive reasonable and necessary funding under the relevant budget depending on support needs. It is useful understand how you can use the funds in each category.

<https://www.ndis.gov.au/participants/using-your-plan/managing-your-plan/support-budgets-your-plan>

3. Getting the right supports in place.

Depending on your situation there are a range of people who can help implement the plan to start receiving supports.

Starting the plan will depend on whether you have elected to:

- Self-manage the plan
- Have a Support Coordinator assist with the plan (if this is funded in the plan)
- Have a LAC help you activate the plan
- Chose to have the NDIA manage the plan

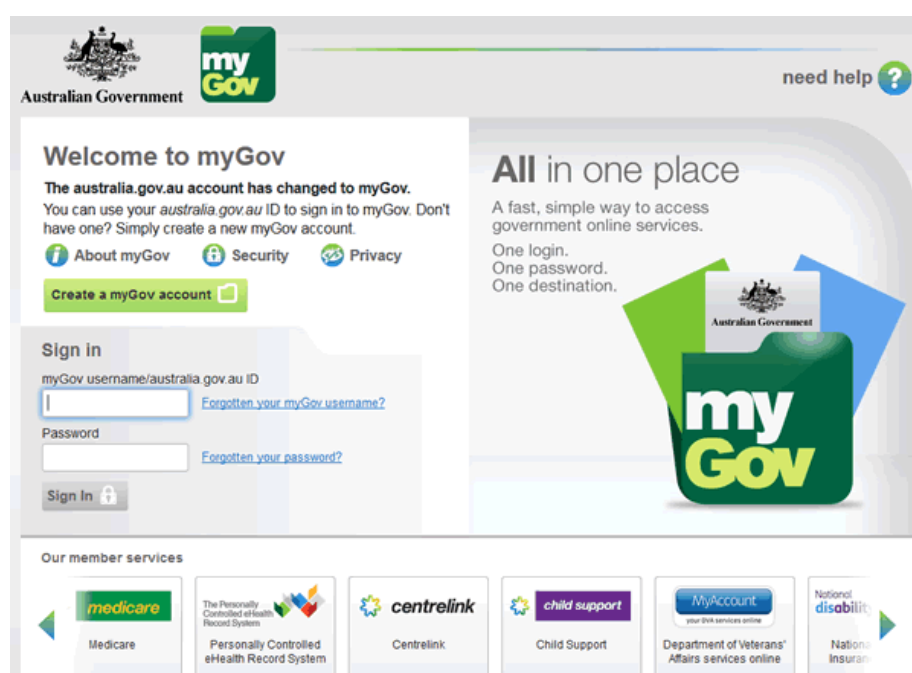
<https://www.ndis.gov.au/participants/using-your-plan>

Remember to register with myGOV!!!

Register for myGov and link to NDIS Participant Portal myplace

There are step-by-step guides to help assist the person you care for access and use myplace. **You will need to link myplace** to the participants myGov account.

<https://www.ndis.gov.au/participants/using-your-plan/managing-your-plan/how-use-myplace-portal>



REVIEW

There are 3 types of review under the NDIS system – an internal review, an external review, and a plan review (scheduled and unscheduled).

An internal Review

Is a process you can go through when you think the NDIS plan is incorrect or there are things missing from the plan that you believe are necessary. You have up to **3 months** to ask for a review..

You can also ask for a review if you disagree with the NDIA's decision not to accept the person you care for into the NDIS.

An external review

Once you have requested a review if you are still unhappy with a decision made by the NDIA you can request an external review by the Administrative Appeals Tribunal (AAT).

The AAT is an independent body that conducts independent merit reviews of decisions made under Commonwealth law such as the NDIS.

You cannot ask the AAT to review a decision until the internal NDIA review has been completed.

For information about applying for an AAT review, visit the AAT website <https://www.aat.gov.au/> or call 1800 228 333.

You can seek support from advocacy agencies with this process and these are listed on the Useful Resources page.

A Plan Review

An NDIS plan is generally in place for 12 months, at which time a scheduled plan review will be conducted by the NDIA or their LAC partner.

A plan review is an opportunity to check if supports are working for the person you care for and helping them work towards, and achieve their goals.

Depending on preference, a plan review can be done face-to-face or over the phone.

If you feel that the person you care for needs are unlikely to change in 12 months' time, NDIA may approve a new plan for up to 24 months. The NDIA is also currently considering extending this to 3 years.

However an unscheduled plan review can be requested at any time, which will bring the scheduled plan review date forward. This usually occurs where there has been a change in your circumstances or if the participant/carer is unhappy with the plan outcome.

Note: If the participant/carer does not agree with the plan, they can ask for a review – in the meantime, you can start implementing the plan, while you are waiting for the review. You have three months after you receive the plan to ask for an internal review.

Change of circumstances

If the participants circumstances change significantly and this affects the supports they need from the NDIS, you can request a plan review by completing the “Request a plan review form”.

Participants of the NDIS and people who are waiting on the outcomes of their “Access request” must by law tell the NDIA of any significant changes in their circumstances.

RECAP

The following flow chart is a recap of all the things we have talked about in this Guide.



SELF CARE

Carers rarely put themselves first. There are always a million things to do and not enough hours in the day to do them. Yet if you don't take some time out for yourself, make some 'me' time, there is every possibility it will impact on your own health and wellbeing.

If you've ever taken a flight you will be familiar with the spiel you receive from the flight attendant either in person or on the screen in front of you. Aside from the usual message of safety belt on, luggage securely placed in the overhead locker or under the seat in front of you, you will be told that in case of an emergency an oxygen mask will drop down and the attendant will demonstrate how to put it on.

You will also be told one more importance thing.

Put your mask on first before you place one on the child or frail/ill person who you are caring for. This simple fact is if don't have enough air you will be unable to help anybody!!!

Carer Wellbeing is important, you are important!

Here are some ways you can self-care,

- Doing Yoga or gentle movement
- Practice mindfulness – breathing and relaxation
- Writing your thoughts down
- Access counselling
- Joining a support group or peer support activity
- Starting a hobby, like painting or gardening
- Connect with services that can help
- Have a conversation with a friend



It is important as a carer to take time for yourself and reach out to others including services for support.

You can use the Carer Gate way to help you with your caring role.

<https://www.carergateway.gov.au/>

Whatever you choose to do, self-care is important and something only you can do.

BIBLIOGRAPHY

Information provided in this document has been sourced (May 2019) via the following sites:

- Reimagine website, Supporting people living with mental health conditions to navigate the NDIS: <http://reimagine.today>
- Endeavour Foundation , supporting people with intellectual disability to live, learn, work and flourish according to their own interests and priorities:
<https://www.endeavour.com.au>
- NDIS website, <https://www.ndis.gov.au>
- Tandem Carers website, a peak body for families and carers of people experiencing mental health challenges and emotional distress in Victoria:
<https://www.tandemcarers.org.au>
- Carers Victoria, <http://www.carersvictoria.org.au/>
- Carers Australia, <http://www.carersaustralia.com.au/ndis-and-carers/what-is-the-ndis/>
- Valid is a Victorian peak disability organisation representing people with an intellectual disability and is operated by people with disability and their families.
www.valid.org.au

USEFUL CONTACTS

- NDIS 1800 800 110: www.ndis.gov.au
- Local Area Coordinator (LAC) offices www.ndis.gov.au/communities/local-area-coordination
- Carers SA: 1800 242 636 www.carers-sa.asn.au
- Action on Disability within Ethnic Communities (ADEC): 1800 626 078 www.adec.org.au
- Carers Australia: 1800 242 636 www.carersaustralia.com.au
- Carer Gateway: 1800 422 737 www.carergateway.gov.au
- Commonwealth Ombudsman 1300 362 072 www.ombudsman.gov.au/making-a-complaint
- Brain Injury SA : 08 8217 7600 www.braininjurysa.org.au
- Disability and Advocacy Complaints Service Inc : 08 7122 6030 www.dacssa.or.au
- Disability Rights Advocacy Service: www.dras.com.au 08 8351 9500
admin@dras.com.au
- Legal Services Commission of SA : 08 8111 5555 www.lsc.sa.gov.au
- Administrative Appeals Tribunal: [1800 228 333](http://1800.228.333) from anywhere in Australia
- The Growing Space is an independent disability consultation and advocacy for families in South Australia www.thegrowingspace.com.au
- Disability Support Guide Support for people living with disability in Australia
www.disabilitysupportguide.com.au
- Lived Experience Telephone Support Service (LETSS) is a Mental Health telephone support service for everyone. It operates 365 days a year from 5pm – 11.30pm.
Phone: 1800 013 755

LETSS aims to provide

- information about mental health topics
- navigation of the mental health system
- real time support when you need it

Online chat is also available at <https://linkstowellbeing.org.au/services>

- Mental Health Service directory covers a range of non-clinical support services for psychosocial and community based programs in S.A. <https://mhsd.com.au/Search>

NDIS GLOSSARY OF TERMS

The NDIS is full of new terms and phrases. Learning the language will help you to understand the NDIS and how it can benefit the person that you care for. It may also be easier to understand the NDIS and communicate with the NDIA if you have an understanding of their terms. Here are explanations of some of the terms and phrases used by the National Disability Insurance Agency (NDIA).

Access Request Form: An application form a person fills out that the NDIA uses and is part of the information used to decide if a person gets NDIS funding

Access decision: The acceptance or rejection of a person's access to the NDIS by the NDIA

Administrative Appeals Tribunal (AAT): an independent body that reviews decisions made by the Australian Government. In the NDIS, the AAT is the place where decisions are reviewed when there are unresolved disagreements between the NDIA and the person with disability.

Advocate: Someone who supports a person and helps them to understand their rights, needs and want. An advocate can also sometimes speak, write or stand up on a person's behalf

Aspiration: A hope or dream that a person wants to achieve in their life

Budgets: There are three support budgets that the NDIS can fund – *core, capacity building and capital* – which are linked to different types of supports. These budgets have different amounts of money a person receives from the NDIS for different supports in their plan

Carers : Family members or friends who provide unpaid support to a person with disability

Carer Statement – A statement written by the carer which explains the carer's role and their ability to continue to provide this care. Carers can include the carer's statement with the supporting evidence that is sent to the NDIA and/or provide it to the planner at the planning meeting

Choice and control: The NDIS lets people choose what is important to them. NDIS participants decide what support they get and who supports them

Community inclusion: This is making sure that every person (disabled or not) who wants to can access and be involved in an activity or service in the same way as other members of local communities

Community services: Activities and services which anyone can use in the community, for example libraries and sporting groups

Consumer: A person who has in the past received, or is currently getting support for a mental health condition. These people have lived experience of a mental health condition

Coordination of supports (support coordination): One of the support categories in a participant's NDIS plan can be 'coordination of supports'. When a person has funding for this support category they are given help to organise and manage their supports in their plan

Economic and social participation: The way in which a person is involved in our community's society and economy. Economic participation means things like working and getting

paid, volunteering or studying. Social participation includes going to a club or group as well as being a part of and caring for your family and friends

Eligibility: means the person has met the access requirements and can get NDIS funding.

Episodic: A person with a mental health condition may go through times of living well and not living so well. When a person's mental health condition varies in intensity it is known as 'episodic'. If a person's mental health condition is episodic, but this has a long term impact that requires support over a lifetime, they may be able to access the NDIS.

Functional impact: This is the term that is used to describe the type and severity of a person's disability and how it affects the things they need to do and the way they do them

Funded supports: Funds that the NDIS gives the person to pay for support to help the person with daily activities and to reach their goals. These supports must be *reasonable and necessary*

Funded support package: The amount of money that is available to a person in their package for supports through the NDIS. A person's plan will tell them how much money the person gets in their package

Goals (hopes and dreams): Things a person wants to do or achieve in the future that will help them have a good life (see also **Aspirations**)

Guardian: A person who can legally make choices for a person with disability. Parents are usually guardians but some people have the State as their guardians (Guardianship)

Informal supports: The unpaid support a person gets from family, friends and neighbours in their local community

Individual Funding Package: An IFP is the budget that has been approved by the NDIA and allocated to the support categories in the person's NDIS plan

Impairment: The loss or limitation of physical, mental or sensory function on a long-term or permanent basis. For people with mental health conditions this would also include a loss of function on an episodic basis which in many cases leads to long-term or permanent impairment

Insurance principle: Every Australian who is born with a disability or acquires one in their life will get the support they need through the NDIS as long as they meet the eligibility criteria

Lived experience: A person's experience of living with a mental health condition or having a close relationship with someone with a mental health condition such as a family member or partner

Local Area Coordinators (LAC): These are local 'community partner' organisations who work with the NDIA to help people, their families and carers access the NDIS. The LAC will help people write their plan get NDIS funding. They also help people manage their plans and get supports and services from outside the NDIS plan (mainstream and local community based supports). They **DONOT** approve eligibility or the final NDIS and budgets. This is a **NDIA responsibility**

Mainstream services: These are non-NDIS government funded and/or delivered services that are used by everyone. They include health and mental health services, public transport, education, housing and employment services

Mental illness: A mental illness is a diagnosable illness that significantly interferes with a person's cognitive, emotional and/or social ability. Mental illnesses are not always diagnosed and people with these conditions may never come into contact with mental health services. Not all mental illnesses cause impairments

My first plan: A first NDIS plan that the person gets which has their goals and what their budget is for. The plan will last for 12 months unless something changes

National Access Team: NDIA staff members who work in areas around Australia to review NDIS Access applications and decide whether people are eligible to access the NDIS

National Disability Insurance Agency (NDIA): An agency set up and funded by the Australian Government to run the NDIS.

National Disability Insurance Scheme (NDIS): The National Disability Insurance Scheme is the new system of disability support that is being introduced across Australia and aims to give people with disability and their carers more choice and control over their supports.

NDIS Act 2013: the legislation which established the National Disability Insurance Scheme (NDIS) and the National Disability Insurance Agency (NDIA). It sets out the objects and principles under which the NDIS will operate.

NDIS Rules: Rules that are binding secondary legislation passed to add further details and explanation to broad terms of the Act. The most prominent rules which feature regularly are:

NDIS (Becoming a Participant Rules 2016)

<https://www.legislation.gov.au/Series/F2016L00544>

NDIS (Support for Participants) Rules 2013:

<https://www.legislation.gov.au/Series/F2013L01063>

NDIS Operational Guidelines: The Guidelines are statements of approach prepared by the NDIA. They outline the NDIA's internal policy in relation to making various decisions. They are not permitted to contradict the Act or the Rules. They aim to guide (not control) decision makers in achieving consistent results while still responding to the individual participant or applicant.

NDIS Price Guide: A price guide developed by the NDIA that contains the maximum prices service providers can charge for particular supports. Each state and territory has a different Price Guide.

NDIS Plan: An official document from the NDIA that states the goals, individual circumstances, and approved funding the participant will have access to.

NDIS Access Checklist: A checklist to help people find out whether they can join the NDIS.

Nominee: A person who can make decisions for a person that needs help making choices but does not have a formal Guardian. You can have the following 2 styles of nominees.

Correspondence Nominee: can make requests to the NDIA for information as well as receiving NDIS correspondence on behalf of the person

A plan nominee can assist the person with their NDIS plan and supports, such as preparation and reviews of plans as well as managing funding and helping put services in place.

Participant: A person with disability who meets the NDIS eligibility requirements and gets a NDIS plan

Participant statement: Information about a person's living arrangements, relationships, supports, description of day-to-day life as well as their aspirations and short and longer term goals

Permanent: This is when a condition will not go away and will be lifelong. To be eligible for the NDIS the person needs to have a condition or impairment that is permanent or like to be permanent (also see *Episodic*)

Plan manager: A person or organisation that manages on behalf of the person their NDIS funds for the supports in a person's plan. This includes paying supplier invoices, developing service agreements with providers, contracting and paying providers and preparing monthly reports on how funds are being used

Plan review: This is when a person meets with the planner to see it needs to be changed. A person's NDIS plan is reviewed at least every 12 months but also if a person's circumstances change

Provider: Someone who operates a service or has things to sell to people who have NDIS funds. People can choose the provider they want to use and change providers if they are not happy – this is choice and control. The NDIS has a list of registered providers but the person can choose unregistered providers if they are self-managing some or all of their funding

Psychosocial disability: This refers to the social and economic consequences related to a mental health condition. It is used to describe the challenges, or limits, a person experiences that are related to their mental health condition. These challenges and limited or impairments are defined as a disability that can affect a person's ability to participate fully in life

Reasonable and necessary: Reasonable means that it is fair. Necessary means the person really needs it. The NDIS will give money for things that are fair and the person really needs to live a good life against the challenges of their disability

Self-management (funding): When a person manages their NDIS money pays providers directly or through a Plan Manager. A person can manage all of their NDIS money or part of it

Service agreement: A document that explains what supports a provider will give the person, how much it will cost, how the person will pay them and what the person needs to do if they want to change providers

Support categories: Funding in a person's NDIS plan is divided into three support categories;

Capacity building supports that help build a person's skills for the future. An example of this is funding for support coordination to help with carrying the person's NDIS plan

Core supports that provide direct help with daily activities. An example of this is help with housekeeping especially at time when the person's mental health is poor

Capital supports that are funded under this category support people to build their independent skills. These are devices and/or equipment that may help the person participate in the community. An example of this might be an electronic calendar to help the person remember and be on time for appointments

Participant - a person with disability who has an individual support plan and their supports paid for by the NDIS.

Peer Mentoring or Peer Support - where a person with a lived experience helps a person new to that experience

Personal care - helping people care for themselves, for example, help with bathing, going to the toilet or eating

Planner - a person who works for the NDIA or NDIA partner (LAC) and whose job it is to help people put together their individual support plans.

Planning meeting – a conversation where a planner, a person and any other support person work together to develop an individual support plan for the participant.

Reasonable and necessary supports – supports that are related to the participant's disability, are likely to help the participant and take into account informal supports provided by families, carers and the community. 'Reasonable' means something that is fair, and 'necessary' means something the person must have

Short-term accommodation – STA (Respite) – short break from the caring role that can include in-home respite, day care and residential respite

Significant, permanent disability – a disability that a person will have for the rest of their life and that makes it difficult for the person to do everyday things without assistance

Support worker – a person who is paid to provide care and support to a person with disability

Therapist: A person whose job it is to treat a particular type of psychological or physical condition, usually with a particular type of therapy (e.g. physiotherapy, occupational therapy, psychologist). In Australia a therapist is usually registered with or is a member of a professional association.

Therapy: therapy is a method of treatment or rehabilitation generally separate from the use of drugs or surgery.

NOTES

NOTES

NOTES