Who is this guide for?
This guide is for people who provide unpaid care and support to a family member or friend with a psychosocial disability* associated with a mental illness or mental health condition.

*Words and acronyms in bold are explained at the end of this guide.

Where is this guide available?
This guide is available from the Mental Health Australia and Carers Australia websites:
www.mhaustralia.org
www.carersaustralia.com.au

What is psychosocial disability?
You might notice some differences between the terms used in National Disability Insurance Scheme (NDIS) materials¹ which refer to “impairments” attributable to a “psychiatric condition” and “reduced psychosocial functioning”, and this guide, which refers to psychosocial disability.

Mental Health Australia and Carers Australia prefer to use the term psychosocial disability, which describes the experience of people with impairments and participation restrictions related to mental health conditions. These impairments can include a loss of ability to function, think clearly, experience full physical health, and manage the social and emotional aspects of their lives.

Psychosocial disability relates to the ‘social consequences of disability’—the effects on someone’s ability to participate fully in life as a result of mental ill-health. Not everyone with a mental illness will have a level of impairment that will result in a psychosocial disability.²

¹ Available at: www.ndis.gov.au/about-us/information-publications-and-reports
# What information can I find in this guide?

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Mental health and the NDIS

What is the NDIS?
The NDIS is a new way of providing support for people with disability. The NDIS aims to give people with disability more choice in how they are supported, and to provide funded support for each individual participant, tailored to their specific needs. The National Disability Insurance Agency (NDIA) is in charge of running the NDIS.

The NDIS is being gradually introduced across Australia in stages, through what are called ‘trial sites’. These trial sites are only in certain areas and sometimes only for certain age groups. Eventually the NDIS will cover everyone with a disability who is eligible throughout Australia. To find out where these trial sites are, visit the NDIS website www.ndis.gov.au.

Who is the NDIS for?
Not everyone with a disability will be able to access an individual funded package of support through the NDIS. There are several ‘access requirements’ or rules which determine who can get funded support. To be eligible, an individual must:

- have a significant and permanent (or likely to be permanent) disability, or a need for early intervention;
- live in an area which is an NDIS trial site and meet any age requirements for that area;
- be an Australian citizen, a permanent resident, or a protected Special Category Visa holder; and
- be under the age of 65.

For more information on the access requirements, visit www.ndis.gov.au/people-disability/access-requirements.

How does mental health fit in the NDIS?
The NDIS is not just for people with physical disability, it will also provide support for people with psychosocial disability associated with mental illness. To be eligible for support, individuals must:

- have an impairment or condition which is likely to be permanent (i.e. it is likely to be life-long) and which substantially reduces their ability to undertake certain activities or to perform tasks unless they have:
  - assistance from other people, assistive technology or equipment; or
  - they can’t participate effectively even with assistance; and
  - their impairment affects their social and economic participation; and
  - they are likely to require support under the NDIS for their lifetime.

An impairment which varies in intensity, for example because it is episodic (on and off), may still be considered ‘permanent’ by the NDIA despite variations in support needs.
What are the steps to getting support through the NDIS?

1. Check eligibility using the online NDIS Access Checklist at www.ndis.gov.au
2. Contact the NDIA on 1800 800 110
3. Complete an Access Request Form*
4. Prepare for the planning meeting, think about needs and goals
5. Develop the plan and consider how to manage the supports
6. Meet with the NDIA planner
7. Carers: complete the ‘Mental Health Carer Checklist’ (optional)**
8. Fill out a Planning Workbook***
9. Implement the plan, find service providers and access supports
10. Review the plan

* The NDIA will send this to you. It may include getting a treating doctor or specialist to complete an Evidence of Disability Form, depending on the age and condition of the person you care for.


*** You can access these on the NDIS website by clicking on the following links or typing the website addresses into your internet browser: Planning Workbook (www.ndis.gov.au/document/ndis-planning-workbook) and Getting Plan Ready (www.ndis.gov.au/participants/getting-plan-ready).

For more information on the steps to accessing NDIS supports call the NDIA on 1800 800 110 or visit www.ndis.gov.au.

**DID YOU KNOW?**

In some areas the NDIA runs pre-planning workshops to help people prepare for the planning conversation. Contact the NDIA on 1800 800 110 to find out more.

Some Carers Associations can also assist carers to prepare for the NDIS planning meeting. To find out what support is available for carers in your area, visit www.carersaustralia.com.au/about-us/contact and follow the link to your local Carers Association or call the carer advisory line on 1800 242 636.
How will the person I care for be supported?

A person who has a **psychosocial disability** who is accepted into the **NDIS** is likely to require support from both the **NDIS** to meet their **psychosocial disability** support needs and from the health and mental health system to meet their health and mental health treatment needs.

**Supports the NDIS will fund:**

The **NDIS** will fund **reasonable and necessary** supports that assist a person with disability to undertake activities of daily living and participate in the community. This could include:

- assistance with planning and decision making and household tasks
- assistance to build capacity to live independently and achieve their goals, such as building social relationships, as well as financial management and tenancy management skills
- supports to engage in community activities such as recreation, education, training and employment.

**Participants** can choose how, when and where to access their funded supports, for example through centre-based services, in-home, day services, community access and outreach services.

**Supports funded by the health and mental health systems:**

The health and mental health systems are responsible for assisting **participants** with medical treatment needs, including diagnosis and treatment of psychiatric conditions and **mental illness**. This includes:

- all medical and clinical services such as general practitioners, mental health treatment by psychiatrists or psychologists
- care while admitted in hospital, in-patient and residential care
- medications and pharmaceuticals.

The **NDIS** will not provide these supports.

**Early intervention for mental health**

The **NDIA** advises that people with early signs of a psychiatric condition will be assisted by the health system in the first instance. The supports offered by the **NDIS** assist the person to address the functional impact of their psychiatric condition. The **NDIA** operates on the basis that these supports are generally not the type of assistance that a person requires at the first signs of a psychiatric condition, but may be appropriate for people who have permanent and significant functional impairments as a result of a psychiatric condition.
**NDIS EXAMPLE**

Caleb is 38 years old and experiences delusions and hallucinations due to psychosis. Caleb requires intermittent access to acute clinical care, in addition to his ongoing treatment, and has been hospitalised many times for his condition. Caleb lives alone and has trouble caring for his own health.

Caleb’s initial goals are to improve his physical health through exercise and to get out and see his friends more often. Caleb would also like to find a job and to look at options for studying. Caleb’s NDIS plan includes funding for psychosocial supports that build Caleb’s ability to get out in the community, including training focused on his communication skills, and decision making. It also includes a simple electronic diary to help him plan his day. Caleb and the NDIA talk to Caleb’s mental health services, to ensure that there are timely adjustments to psychosocial supports during and after any acute episodes of care from the clinical sector. A Local Area Coordinator assists Caleb to connect to local TAFE courses about parenting so that he feels he is able to be a stronger dad.


In this example it is clear that Caleb’s health needs (including mental health) are being provided by health services such as a GP, a community mental health team and sometimes, hospital services.

The NDIS will provide Caleb with supports to meet his other goals of doing more exercise and going out with friends.
Why is the involvement of mental health carers in supporting a participant in the NDIS important?

The involvement of mental health carers in the NDIS will often be very important to achieving the best outcomes for participants with psychosocial disability. This is because carer involvement is often crucial to ensuring the:

- assessment of the person with psychosocial disability is accurate and captures the impact of their disability on their everyday functioning
- support plan is appropriate to the participant’s needs and takes account of the role of the carer
- support plan helps to maintain the sustainability of the caring relationship.

What role will mental health carers have in the NDIS?

Different carers will have different roles. The carer’s role depends on what the participant wants, what the NDIA thinks is reasonable and necessary, and what the carer feels they can manage.

The main ways a carer might be involved in the NDIS include:

- supporting the participant to apply for the NDIS
- assisting the participant to prepare for the planning meeting and think about their goals and support needs
- going along to the planning session with the participant
- being listed in the participant’s plan as an informal support
- providing advice on the participant’s support needs

How are carers recognised in the NDIS?

The National Disability Insurance Scheme Act 2013 is the legislation which establishes the NDIS and the NDIA.

The Act says that under the NDIS carers should:

- have peace of mind that the participant will get the support they need for the rest of their life
- be acknowledged and respected for their role in the life of the participant
- have the supports they provide considered by the NDIA, including what type and amount of support is reasonable for them to provide
- have opportunities, if appropriate, to improve their ability to support the participant.

Adapted from the Carers NSW NDIS fact sheet ‘Where do carers fit in the NDIS?’ (see www.carersnsw.org.au/NDIS)

Available at: https://www.comlaw.gov.au/Details/C2013A00020

Adapted from the Carers NSW NDIS fact sheet ‘Where do carers fit in the NDIS?’ (see www.carersnsw.org.au/NDIS)
• helping the participant manage their NDIS plan
• helping the participant access funded services and supports
• supporting the participant during any review of their support plan.

NB: In some circumstances, a carer may be appointed as a nominee, to make some decisions on behalf of a participant. Who the nominee is, and what they will be able to do, will depend on the participant’s situation. For more information on nominees and guardians, see www.ndis.gov.au/families-carers/what-are-nominees-and-guardians.

Consent and information sharing

Some people with a psychosocial disability are unaware of the impact of their illness and the supports they need or receive to do the things they want. In some circumstances this may only occur when people become unwell but for some people, understanding of the extent to which others support them may always be limited by illness or psychosocial disability. This is challenging when the role played by carers is crucial to day to day living and the recovery journey of a consumer.

Participants in these circumstances may not give permission for the carer to be involved in their treatment or in conversations about their support requirements, particularly if they are unwell. This can be distressing for mental health carers who are involved in the ongoing support of a person with a mental illness, and can have an extensive impact on the relationship between consumers, carers and clinicians. This impact includes making it extremely difficult for carers to continue to provide appropriate support if they are unaware of treatment or support arrangements that are made on behalf of consumers.

Suggestions for mental health carers

To ensure you can be involved as much as possible in the support of the person you care for through the NDIS, you may want to consider:

• talking with the person you care for about why your involvement is important for both of you and how you might be able to assist them through the planning process and to access supports
• making an agreement about how you will be involved; i.e. in what parts of the NDIS processes and how
• talking about what will happen when the person you care for is unwell. For example, making an advance directive which outlines what permissions you have as a carer during this time, and what actions they’d like you to take
• letting the NDIA know about any agreements, both formal and informal, that you have with the person you care for about your involvement, and providing the NDIA with any information about advance directives
• you might also want to access advocacy services (such as through a carer association or mental health organisation) to support you as you engage with the NDIA.
Do carers have a say in what support they provide?\(^6\)

Yes, carers do have a say in what support they will provide to an NDIS participant and the NDIA must take this into consideration.

There are a range of NDIS Rules\(^7\) which specify how the NDIS should operate. Some of these Rules include instructions for NDIA staff that relate to carers. For example, the Rules which cover ‘Supports for Participants’\(^8\) state that when the NDIA makes decisions about what supports they will fund for a person with a disability, they must ensure that this support is sustainable. This means they need to consider what is reasonable to expect families and carers to provide and what the NDIA can do to ensure that this support can be provided on an ongoing basis.

In making this judgement the NDIA has to take the following issues into account:

- The age and capacity (or ability) of their carer, and whether they can keep caring in the same way.
- The amount of care they provide, the type of this support and whether it is reasonable for the carer to do these tasks.
- Any risks to the wellbeing of any family members or carers in carrying out their caring role. For example, the NDIA does not expect a child to care for their parents or siblings or to miss out on going to school because of their caring role.
- Any supports the carer might need to help them in their caring role.

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**DID YOU KNOW?**

You can also bring an advocate to the planning meeting to help you and the person you care for discuss their support needs. An advocate is someone who supports and speaks up for people with disability and their carers and may help the person you care for to make decisions about their needs, goals and preferred supports. An advocate may be another family member or friend, a paid worker from a disability advocacy organisation, a staff member from a carer organisation or a disability provider, or anyone you and the person you care for choose.

The National Disability Advocacy Program (NDAP) provides people with disability access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling community participation. NDAP can provide advocacy services to people with disability by making sure they have a support person. For NDAP agencies based in the NDIS trial sites, there are additional roles which may include assisting people through the planning and review processes with the NDIA. To find out more about advocacy support through the NDIS, visit [www.ndis.gov.au/participants/making-decisions-about-support/ndap](http://www.ndis.gov.au/participants/making-decisions-about-support/ndap) or call the NDIA on 1800 800 110.

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\(^6\) Adapted from the Carers NSW NDIS factsheet ‘Where do carers fit in the NDIS?’ (see [www.carersnsw.org.au/NDIS](http://www.carersnsw.org.au/NDIS))


Can carers go to the planning session?

**NDIS participants** can choose to bring anyone they want to the planning meeting. This includes carers, family members, friends or a paid support worker.

The **Operational Guidelines** which are designed to assist the **NDIA** in making decisions include recommendations about involving carers in the assessment and planning conversation. These Guidelines state that the **NDIA** should establish the impact of providing informal support to the carer and establish the carer’s ability to continue to provide the same level of support. The guidelines also state that in some circumstances, this may need to be discussed in a separate conversation with the carer.

Can carers have a separate discussion with the NDIA?

In some circumstances, carers may be allowed to have a separate discussion with the **NDIA** about their caring role. This will depend on individual circumstances such as the age, impairments and support needs and of the **participant**, whether their permission is required, and if the **NDIA** thinks it is appropriate for carers, family or others to be involved.

If the person you care for is over 18 years and doesn’t consent to you speaking privately with the **NDIA**, you might consider developing a written Carer Statement (which describes how you support the **participant**) and submitting this to the **NDIA**.

What is a Carer Statement?

During the planning process the **NDIA** will engage with carers to ensure their circumstances and ability to sustain their caring role is considered in relation to the **participant**’s support needs. Any information about the carer’s capacity is then recorded as a Carer Statement on the **participant**’s record so that this can be revisited at review. The carer may request to have this conversation in absence of the **participant**, and if appropriate, the **NDIA** will facilitate this.

Carers can also choose to prepare a written Carer Statement beforehand and bring this to the planning meeting or submit it to the **NDIA**, though this is not compulsory.

A Carer Statement (in written or verbal form) may cover the following information:

- Carer goals which impact on their informal care provision and sustainability of informal care for the **participant**.
- Current capacity and any limitations with providing care or support to the **participant**.
- Other informal support networks available to the **participant** (e.g. other family members or friends who also provide support).

There is no template for the Carer Statement, but you might find the ‘**Mental Health Carer Checklist to Prepare for NDIS Assessment and Planning**’ developed by Carers Australia and Mental Health Australia useful. Carers NSW has also developed an **NDIS checklist** for carers (‘**NDIS checklist for carers in NSW**’) which may also be useful for carers in other states and territories.

**REMEMBER...** if you are not confident in making a written statement, you can still talk to the **NDIA** about how you support the **participant**, what your goals are and whether your caring role is sustainable. This will then be recorded by the **NDIA** as a Carer Statement on the **participant**’s record.

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**Available at:**
Why is a Carer Statement important?

The NDIA has a commitment to make informal caring arrangements sustainable and to take account of what is reasonable to expect family and friend carers to provide.

Where a Carer Statement is submitted, this helps the NDIA to assess the supports they will fund for the participant by considering the participant’s living arrangements, who supports them and how, the future plans of the carer which may affect their caring role and their ongoing ability to provide care.

What do I need to tell the NDIA?

Some of the things you might want to discuss with the NDIA either in person or in a written Carer Statement may include:

- the mental health condition of the person you care for and how it affects their everyday functioning and support needs. This should include any changes that may occur when they become acutely unwell
- the person’s strengths and how you nurture those
- the different ways in which you support the person (i.e. the type of care you provide), and how often you do certain caring tasks
- any impact on your own health and wellbeing (and that of family members) as a result of your caring role
- whether you are willing and able to keep going in your caring role
- whether you need any additional support or assistance to help you in your caring role.

You might find the ‘Mental Health Carer Checklist to Prepare for NDIS Assessment and Planning’ useful in preparing for your conversation with the NDIA. This checklist is available on the Mental Health Australia (www.mhaustralia.org) and Carers Australia (www.carersaustralia.com.au) websites.

Can carers get support through the NDIS?

Carers are not participants of the NDIS in their own right and so won’t receive a separate assessment of their own needs or an individual funded package of supports. However, there are a range of supports which may be included in a participant’s plan which can assist carers in their caring role. This includes supports such as:

- training for carers in how to care for a person with a disability or in how to manage certain difficult behaviours
- group or family therapy
- assistance with decision making, daily planning, budgeting and life/transition planning (e.g. to plan for changing needs and circumstances)
- respite like supports, noting these supports will not be called respite in the plan.

There are also a range of supports which provide care for a person with disability, which may provide a respite-effect for families and carers by providing a break from the caring role. This includes supports such as:

- Overnight assistance with self-care
- Assistance in a host family or alternative family situation
• Short term accommodation and assistance in a centre or a group residence

• Specialised home based assistance for a child with disability in order to sustain informal supports.

Whether the NDIA will include any or all of these supports in the plan of the person you care for will depend on individual circumstances, such as the nature of a person’s disability or impairment and the appropriateness of the support for that individual. Access to supports such as direct respite will also depend on the availability of those services in the area that participants and their carers live.

Other supports for carers

There are a range of supports available to carers outside of the NDIS including respite support, counselling, education and training, peer support and advocacy. For information about what carer supports and services are available in your area, call the National Carer Advisory Line on 1800 242 636.

To contact your nearest mental health carer organisation, visit: www.arafmiaustralia.asn.au/ or call:

**VIC & SA**: 1300 550 265

**NSW**: 1800 655 198

**QLD**: 1800 35 1881

**NT**: 1800 985 944

**WA**: 1800 811 747

**TAS**: 03 6228 7448

**ACT**: 6296 9900 | 1800 242 636

What if there is a disagreement with a decision made by the National Disability Insurance Agency?

Certain decisions which are made by the NDIA can be reviewed if the participant, or you on their behalf, doesn’t agree. These decisions are called ‘reviewable decisions’. This includes decisions such as being accepted as a participant or whether a particular support will be funded by the NDIA. A list of reviewable decisions is in the NDIS Act.11

Key things to remember:

• Before asking for an internal review, you may want to consider asking the original NDIA staff member to reconsider their decision.

• If you decide to request a review, you need to do so within 3 months of receiving notice of the original decision.

• A request for review can be made by writing a letter, by calling the NDIA, by sending an email, or in person.

• You need to explain why you think the decision is incorrect, and if making a request in writing, you may want to use the NDIA ‘application for review of a reviewable decision’ form,12 but this is not compulsory.

• If you are still unhappy after the first review you can either

  • Seek a further review by the NDIS, or

  • Ask for a review by the Administrative Appeals Tribunal (AAT).

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11 Available at: www.comlaw.gov.au/Details/C2013A00020

12 Available at: www.ndis.gov.au/document/application-review-reviewable
DID YOU KNOW

Through the National Disability Advocacy Program (NDAP), funding is available to provide assistance to people with disability seeking a review of NDIA decisions through the Administrative Appeals Tribunal. There are support persons available to ensure the external merits review system is accessible and as non-adversarial as possible for people with disability. All applicants seeking external merits review by the AAT are entitled to a support person provided through one NDAP provider in each launch site.

See contact details below:

**New South Wales (Hunter)**
Disability Advocacy NSW
(02) 4927 0111 or 1300 365 085
www.da.org.au

**Victoria (Barwon)**
Regional Information and Advocacy Council
(03) 5245 7986
www.riac.org.au

**Australian Capital Territory**
ACT Disability, Aged and Carer Advocacy Services
02 6242 5060
www.adacas.org.au

**South Australia**
Brain Injury Network of SA Inc
(08) 8217 7600 OR 1300 733 049
www.binsa.org

**Western Australia (Perth Hills)**
Midland Information Debt & Legal Advocacy Service (MIDLAS)
08 9250 2123
www,midlas.org.au

**Tasmania**
Advocacy Tasmania Inc.
1800 005 131
www.advocacytasmania.org.au

**Northern Territory (Barkly)**
Brain Injury Network of SA Inc
1300 733 049 OR (08) 8217 7600
www.binsa.org
Where can I go to find more information?

For fact sheets on the NDIS for mental health consumers and carers developed by Mental Health Australia visit www.mhaustralia.org.

For fact sheets on the NDIS for carers developed by Carers NSW visit www.carersnsw.org.au.

For the Carers Australia NDIS webpage visit www.carersaustralia.com.au/ndis-and-carers/

For more information about the NDIS visit www.ndis.gov.au or call 1800 800 110.
Key terms

**Advance directive**
An advance directive is a document prepared by a mental health consumer to be read and used in case of a mental health crisis. Typically, advance directives contain special information outlining a person’s unique circumstance, personal preferences regarding treatment choices and information about practical life management arrangements. An advance directive outlines the steps that must be taken to provide optimal support and care for a person with a mental illness during a time of crisis in order to limit or prevent the damage from that crisis.¹³

**Advocacy**
Advocacy aims to increase a person’s control over goods, services and quality of life, to develop a sense of empowerment and of being valued as an individual. Advocacy focuses on the needs, wishes and rights, including protection of confidentiality, of that person. Advocating may involve asking for change or challenging what is unfair, unjust and wrong.¹⁴

**Early intervention**
Providing supports to a person with disability early on to reduce the amount of support they may need in the future.

**Individual funded package (IFP)**
Eligible NDIS participants receive an individualised plan which outlines the supports which will be funded by the NDIS. This is called an individual funded package.

**Mental health carer**
Someone who provides unpaid care and support to a family member or friend with a mental illness or mental health condition. A carer may or may not live with the person they support, and may not be identified by the individual with a mental illness to be their carer.

**Mental health condition**
Describes the broad range of features that characterise a mental illness whether diagnosed or not.

**Mental health consumer**
A person with a lived experience of mental illness or a mental health condition. Also referred to as a consumer.

**Mental illness**
Diagnosable illness that significantly interferes with an individual’s cognitive, emotional and/or social ability.

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NDIA
National Disability Insurance Agency. The NDIA is in charge of running the NDIS.

NDIS
National Disability Insurance Scheme.

Nominee
A person who has been requested or named to act on behalf of another.

Participant
An individual who is an eligible participant in the National Disability Insurance Scheme.

Psychosocial disability
An internationally recognised term used to describe the experience of people with impairments and participation restrictions related to mental health conditions. These impairments can include a loss of ability to function, think clearly, experience full physical health, and manage the social and emotional aspects of their lives.

Reasonable and necessary
The NDIS will only fund supports which they determine are reasonable and necessary to help a participant reach their goals and to undertake activities to enable the participant's social and economic participation. There are many factors that the NDIA consider in deciding what is reasonable and necessary. For more information see: www.ndis.gov.au/participants/reasonable-and-necessary-supports.

Respite
A short break from the caring role that may include replacement care in the home, activities outside the home for the person receiving care, or replacement care in a residential facility.