

Supporting communication in and contribution to NDIS planning conversations



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About this resource

This resource is for autistic adults with complex support needs and their parents and carers who have been accepted into the National Disability Insurance Scheme (NDIS).

People who have been accepted into the NDIS are known as NDIS participants.

Amaze made this resource to help you prepare, plan and participate in planning conversations for the NDIS. Inside you will find practical strategies that can support communication and participation for autistic adults with complex support needs and their carers. The resource has been designed in two parts - Part 1 for parents and carers and Part 2 for autistic adults with complex support needs.

Amaze would like to thank the autistic adults with complex support needs and parents and carers who completed the surveys and consulted with us about their experiences in NDIS planning conversations. Thank you to VALiD, the Office of the Public Advocate and to the following services who assisted with the surveys for autistic people with complex support needs; Broadmeadows Disability Services, Latrobe Lifeskills and Araluen. We thank the Department of Health and Human Services for funding the development of this resource.

About Amaze

Amaze is the peak body for autistic people and their supporters in Victoria.

Our aspiration is to shape a society that respects the dignity of every autistic person and offers them real opportunities to participate and contribute.

We provide free, independent and expert information to more than 200,000 people each year through our Autism Advisor helpline, website and workshops. The Autism Advisor service is available 8am to 7pm Monday–Friday on 1300 308 699, info@amaze.org.au or at www.amaze.org.au.

Part 1: Supporting communication in and contribution to NDIS pre-planning for parents and carers of autistic adults with complex support needs

The introduction of the NDIS has been a huge change in the disability community. During Amaze's consultations with autistic adults with complex support needs and their parents and carers we learnt that there is still work to be done to improve the level of support for NDIS participants to communicate and contribute to planning conversations about their future.

In Part 1 we give an overview of key terms such as rights, the NDIS, person centred planning, goals, choices and decision making. Next we provide questions about the communication and participation preferences of the person you care for (the NDIS participant) when preparing for the NDIS planning meeting.

There are also some suggestions for ways an NDIS participant can contribute to a planning meeting even if they're not attending. The section on things to think about before your NDIS planning meeting aims to give the NDIS participant choices, for example, attending the NDIS planning meeting, the meeting timing and location. At the end of Part 1 there's a glossary and a list of resources.

Rights for Australians with a disability and the NDIS

The NDIS funds reasonable and necessary supports for Australians with a disability. Parents and carers have a key role in supporting the participation of those they care for in developing goals for NDIS plans and in NDIS planning meetings. In order to advocate for your NDIS participant it can be helpful to understand some of the principles that are in the NDIS Act 2013.

These include:

(9) People with disability should be supported in all their dealings and communications with the Agency and the Commission so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs.

(12) The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected.

There is more about rights and the NDIS on page 7.



Preparing for your first NDIS planning meeting? Go to the [Amaze NDIS planning hub](#) for downloadable resources including a preparation checklist.

You can work with the NDIS by advocating for the support needs of the NDIS participant. The NDIS can fund reasonable and necessary supports related to the person's disability for example personal care, community participation, specialised disability accommodation, skill development, behaviour support. A complete list of funded supports is available on the NDIS website. The [NDIS website](#) has resources, many available in Easy English or video format, to support people before and during the planning process.

If you disagree with a decision made about the plan of the person you're caring for, for example, if reasonable and necessary supports weren't funded, you can request a review by contacting the NDIA. You need to request a review within three months of receiving your plan.

Person centred planning

Person centered planning (PCP) is a way that people are supported. It means that the person receiving the supports is at the centre of any planning and decision making. This can be before planning, during planning and when support is being delivered.

Person centred planning may include not only parents or carers, but other people who have spent time with the person. It may also include therapists and other support staff who have useful information to contribute about therapy goals or daily support needs.

Any planning that is done must have the autistic person at the centre. For autistic people with complex support needs, person centred planning may mean that the person participates as much as they want to, or as much as they are able to.



If the person you care for can't make decisions you may be appointed by the NDIA as a [plan nominee or a correspondence nominee](#). This means you can ask or make decisions on behalf of the person. A guardian can also be appointed as a plan nominee. Read more about [guardians and nominees](#).

Participation

One of the assumptions underlying the NDIS is that people with a disability can, and want to, participate in the planning process. Attending a meeting in person or understanding paperwork and complex concepts relating to the NDIS may be a barrier for many autistic people with complex support needs.

An autistic person with complex support needs may find attending meetings challenging. They may require additional support, or not fully understand the purpose of the meeting. Partial participation seeks other ways to contribute to the meeting. This includes situations where a person knows what they want for one part of their life, such as a favourite activity, but may not be interested, or fully understand, other parts of their supports, such as finances or health management.

Participation can range in type and amount. For example, it can be verbal or written. It can be attending a meeting in person or recording a video as a contribution to the meeting. A person centred approach means that autistic people with complex support needs can participate in the way they would like to and contribute as much as they need to, or are able to, in the NDIS planning meeting.

“My son didn’t attend the meeting. Instead I made a timeline of his life with photos of his favourite activities, his dog and a picture of him at his last birthday surrounded by family and friends. It helped the Planner to know who is and what his life is like.”

Goals and choices

The NDIS wants participants to identify goals they would like to work on. Goals are things you would like to do, work towards, and achieve in life. In order to set goals people need to make choices. For autistic people with complex support needs understanding goals may be difficult. It may be easier to talk about making choices that can lead to a goal. For example if the participant enjoys coffee, the goal may be to learn to make coffee.

When thinking about the sorts of goals you would like in the NDIS plan, focus on what is reasonable and necessary – there’s more information on this on the [NDIS website](#). For example the NDIS won’t fund train tickets but may fund support for travel training or to visit places like railway museums. When talking with the participant, limiting choices may guide what is reasonable and necessary.

Some autistic adults with complex support needs may not want to set goals or make choices about all parts of their lives. For example, making a choice and setting a goal about your favourite activity is different to setting goals about behaviour or personal care.

‘The things I want to have a say in’ resource is designed for autistic adults with complex support needs. You can use this resource to talk about rights, goals and choices with the person you care for.

“We talked about his goals before the meeting and practised what he wanted to say.”

Your rights when it comes to the NDIS and making decisions

The following information has been reproduced from VALiD to help you in advocating for the NDIS participant.

- You have the right to be part of your NDIS planning meeting and to have the support you need to participate.
NDIS Act 2013, section 17A & section 31
- You have a right to make decisions about your goals, the services you use, and to choose who helps you to make your NDIS plan happen.
NDIS Act 2013, section 4
- You have a right to have information about your NDIS plan and supports in ways that you can understand.
Commonwealth Disability Discrimination Act 1992, section 6
- You have a right to choose who supports you when you need to talk with the NDIS about your plan.
NDIS Act 2013, section 4
- You have a right to have your wishes taken into account, even if you need full support from family or friends, or a formal representative, to make decisions (e.g. a Guardian, Power of Attorney, Plan Nominee).
NDIS Act 2013, section 5; United Nations Convention on the Rights of Persons with Disabilities, Article 12; Guardianship and Administration Act 1986 (Vic) section 22

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Communication and meeting preferences for people with complex support needs

The questions in this section can be used before your NDIS planning meeting to think about the communication and meeting preferences of the person you care for. Knowing a person's communication and meeting preferences offers opportunities for people to contribute and participate in planning, before a meeting, at a meeting, or both.

1(a) How does the person communicate with you?

- Verbally
- Gestures
- Blinking
- Communication Board
- Sign
- Other _____(please specify)

1(b) How does the person communicate with others?

- Verbally
- Gestures
- Blinking
- Communication Board
- Sign
- Other _____(please specify)

2. What language do they use?

3(a) Would the person like to attend the planning, or review, meeting with the Local Area Coordinator (LAC) or Planner?

Yes or no (circle one)

3(b) If yes

- For the whole meeting
- For some of the meeting

3(c) Would the person prefer the meeting to be held

- At the LAC office
- At home
- Other _____(please specify)

4. Would something in the meeting space need to be changed for the person to attend the planning or review meeting with the Local Area Coordinator (LAC)?

5. What changes are needed for the person to attend the planning or review meeting with the Local Area Coordinator (LAC)?

- No fluorescent lights
- Quiet space
- Interpreter
- No perfume
- Other _____(please specify)

Options for participating in the planning or review meeting when the person isn't attending;

- A written statement about what the person likes to do and their goals for the next year.
- A video showing what the person likes to do and their goals for the next year.
- Photos of the person doing activities that they enjoy and/or are important to them, for example, work or study and their goals.
- Drawings by the person about what they enjoy, what's important to them and their goals.

Ideas for supporting material when the person is attending;

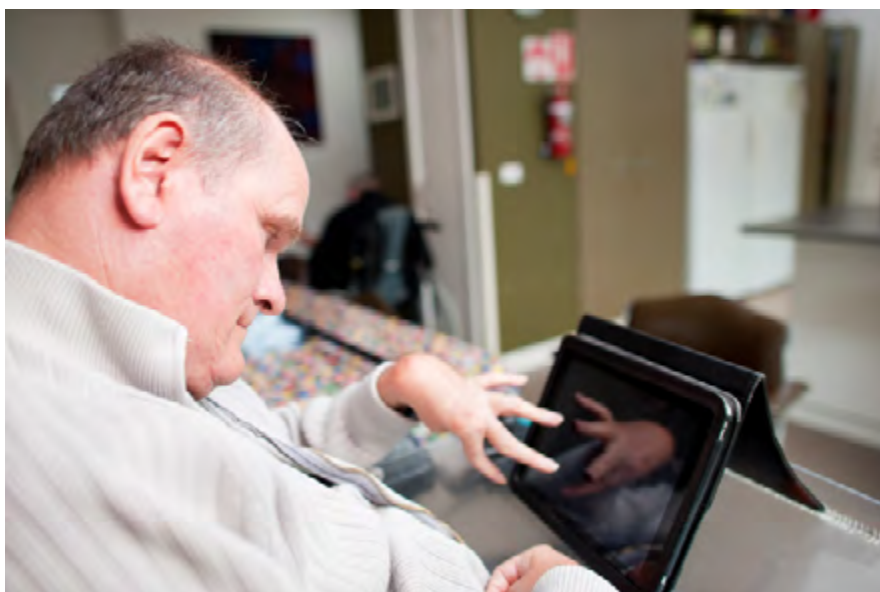
- Photos, videos, drawings, items or written statements that help the person to communicate about their interests and goals.

NDIS meeting guide

Before the meeting

Here are some suggestions about things to think about before the NDIS planning meeting.

- Decide whether the NDIS participant will attend part or all of the planning meeting.
- Think about what location and time of day for the planning meeting will be best for the person you care for, for example, your home or another familiar location. Talk to the LAC or Planner about when and where the meeting can be held.
- Arrange for a support person or worker to attend the planning meeting with the person you care for. This may offer you the opportunity to focus on the planning meeting. The support person can take the person for breaks when needed or help them to leave the meeting.
- Let the LAC or Planner know if the person you care for may need breaks during the meeting.
- To determine the level of support needed negative and personal issues may be discussed at the planning meeting. Think about whether the NDIS participant needs to be part of this discussion. Some parents and carers reported that hearing about these issues can trigger anxiety in the person they care for.



NDIS meeting guide

- Let the LAC or Planner know if the NDIS participant doesn't want negative or personal issues discussed in front of them or finds them uncomfortable.
- If you're unsure how the NDIS participant feels about talking about negative or personal issues you can ask them. Let them know that the LAC or Planner wants to know about these issues to work out what supports they need in their NDIS plan.
- Ask the LAC or Planner to use the communication method that the NDIS participant uses in the planning meeting.
- Ask the LAC or Planner for a list of questions that they'll ask the NDIS participant in the planning meeting. Use this list to practise the answers together before the meeting.
- Think about whether you want to use social scripts, visual supports or prompts for the NDIS participant at the planning meeting. Prepare any visual supports or prompts.
- Use the NDIS Easy Read booklets and factsheets to help the NDIS participant understand the NDIS. There's a link in the Resources section on page 14.

If the meeting is at the LAC's office;

- Ask if the LAC/Planner can provide visual supports about their office or meeting venue.
- Think about anything else you need to email to the LAC/Planner before the meeting eg. letting them know that the NDIS participant needs more time to read information or that they are non-speaking.

"My daughter gets very anxious meeting new people in unfamiliar locations. We talked about her goals and she decided that she'd like me to attend the planning meeting as her representative."

Glossary

Plain English is a style of writing that is clear and concise. Resources written in this style will avoid or reduce technical jargon. Sometimes this is called 'layman's writing'.

Easy English or Easy Read are resources that have been designed for people who may have low English literacy. Often easy English resources have pictures or photos accompanying text.

Person centred planning is a way that people are supported. It means that the person receiving the supports is at the centre. This can be before planning, during planning and when support is being delivered.

Visual Supports are photos, drawings or illustrations that are used to help an autistic person access information.

Social Script is a visual story that describes a social situation. It is written in positive language and lets people know what is going to happen. The script will also have strategies for managing a situation e.g. asking for a break. Social scripts usually contain photos or illustrations to support the text.

Advocate is a person who supports you in various type of meetings or interactions. They may support a person by just being in the room with them. There may be situations where a person has given consent for an advocate to speak on their behalf. Advocates can be trusted people like family or friends, or a person from an advocacy organisation.

Office of the Public Advocate a state government organisation that promotes and protects the rights and interests of people with disability.

Partial participation is the idea that people with a disability can participate in areas in their lives as much, or as little, as they are able or like too.

Local area coordinator (LAC) is a person employed to assist people to navigate the NDIS, including planning and coordination.

Planner is a person who works for the NDIS who helps people with a disability and their parents or carers to put together a plan and apply for funding.

Glossary

National Disability Insurance Scheme (NDIS) is how the Australian Government provides support to Australians with disability, mental health issues, chronic illness and who are Deaf.

Behaviours of concern are very difficult or serious behaviours that reach a level where an individual hurts themselves or others. For example, hitting, punching and biting, inappropriate sexual behaviour or wandering.

Nominee a person who is chosen to make decisions for a participant who doesn't have a parent or guardian.

NDIS participant a person with a disability who has been accepted into the NDIS.

Guardian a person appointed by the Victorian Civil and Administrative Tribunal (VCAT) to make personal and lifestyle decisions for an adult with a disability who is unable to make reasonable judgements. Parents can be appointed guardians or fulfil this role informally.

Support worker a person who is employed to help a person with a disability, for example with personal care.

Planning meeting is a gathering of the LAC or Planner, the individual with a disability if possible and their carer(s) and support person to discuss an individual's NDIS plan.

Goals are things you would like to do, work towards, and achieve in life.

Support coordinator a person who is funded under a NDIS plan when the participant is not able to implement and coordinate their own plan.

Read more about NDIS terms:

- [NDIS concepts in Auslan and an Easy Read glossary](#)

Resources

The **Amaze Autism Advisor** service is available 8am to 7pm Monday–Friday on 1300 308 699, info@amaze.org.au or at www.amaze.org.au.

The [Amaze NDIS Readiness Resource](#) can also be completed by either a carer or autistic individual

[Carers Victoria NDIS Carers Handbook](#)

The [NDIS website](#) has resources, many available in Easy English or video format, to support people before and during the planning process.

In particular:

- [How the planning process works](#) information for carers
- [Participant booklets and factsheets](#) including Easy Read booklets and factsheets.

Office of the Public Advocate

Office of the Public Advocate Advice Service Monday to Friday 9am to 4:45pm.

The Advice Service provides advice on issues that affect people with a disability including guardianship and enduring powers of attorney.

Telephone: 1300 309 337

TTY: 1300 305 612

Fax: 1300 787 510

National Relay Service: 133 677

Email: OPA_Advice@justice.vic.gov.au

Resources

[NDIS decision-making poster, Working with participants with a significant cognitive disability](#)

A series of [nine videos presented by VALiD](#) about the NDIS planning process, funding management and more.

A [short video on why future planning is important](#) from The Arc for people with intellectual and developmental disabilities.

The [resources section of the Communication Rights Australia website](#) has infographics on Augmentative and Alternative Communication (AAC) and on The NDIS at a Glance.

The [Advocacy for Inclusion Supported Decision Making podcast](#) includes episodes on rights, decision making, supporting people to communicate and more.

Part 2: Having a say in the NDIS - booklet for autistic people

Easy English



What is the NDIS?



The National Disability Insurance Scheme pays for disability supports in Australia. People call it the NDIS.



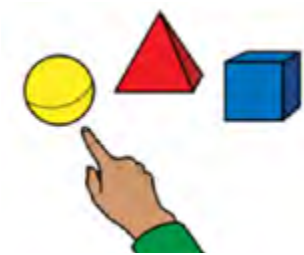
The NDIS want to know what things you want or need in your life.



Some of these things will be big. Some of these will be small.



NDIS will fund things that are fair. This means things that people need to live their life.



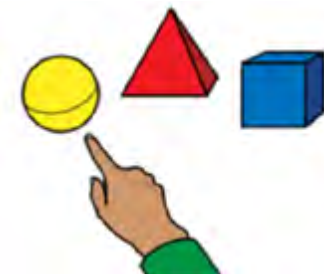
You should get to choose the things you need that will help you live your life.



Your rights



You have the right to be part of your NDIS planning meeting. You can have the support you need to participate.



You have a right to make choices about your goals. You can choose who helps you to make your NDIS plan happen.



You have a right to have information about your NDIS plan in a way that you can understand.

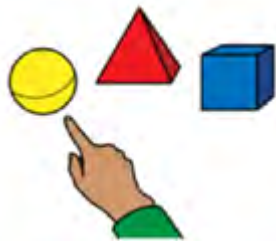


You have a right to choose who supports you when you need to talk with the NDIS about your plan.

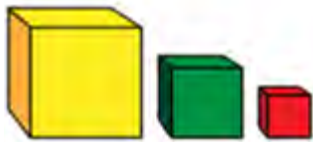


You have a right to have your wishes heard. If you need full support from family or friends, or a formal advocate, to make choices they should say your wishes.

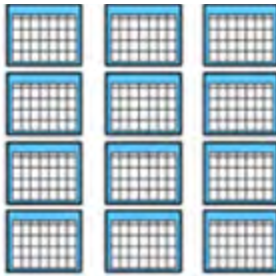
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Choice and Control



The NDIS will want you to make choices. Some will be big. Some will be small.



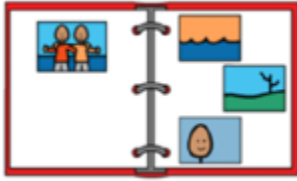
You may have a big goal that you are working towards.



You may have lots of smaller goals that will help you get to your big goal. The NDIS can help you with that.



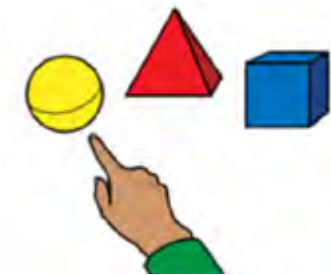
You may want to have a say about daily choices. This can be the things you do each day.



Sharing your story



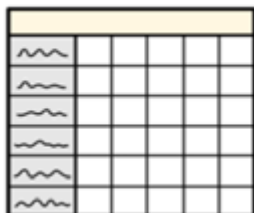
NDIS will want to hear your story. This is so they know who you are and what you like.



There are many ways to share your story. You can choose what is best for you.



Write a story about your life.



Share a schedule of your favourite day.



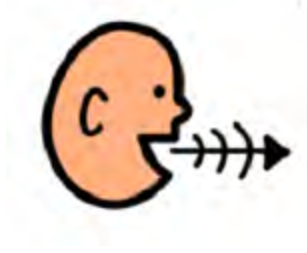
Share your favourite photos.



Make a drawing or collage to share.



Show people from the NDIS the things you like.



Tell them in the meeting.



Make a video.



Make an art project.