

# Home and Living Reference Group

An Easy Read meeting bulletin

9 November 2023



## How to use this bulletin



A **bulletin** is an important news item we share with the community.

It explains what we did in our meeting.



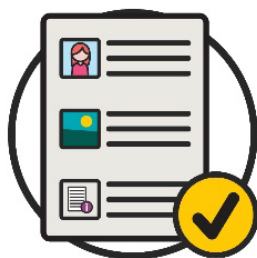
The Independent Advisory Council gives advice about ways to make the NDIS better.

In this bulletin, we just say IAC.



The IAC wrote this bulletin.

When you see the word 'we', it means the IAC.



We wrote this bulletin in an easy to read way.

We use pictures to explain some ideas.

# **Bold**

We wrote some important words in **bold**.

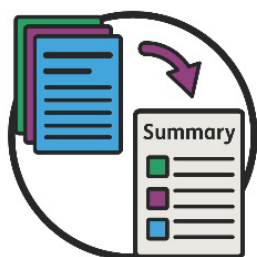
# Not bold

This means the letters are thicker and darker.



We explain what these bold words mean.

There is a list of these words on page 31.



This Easy Read bulletin is a summary of another bulletin.

This means it only includes the most important ideas.



You can find the other bulletin on our website.

[www.ndis-iac.com.au/meetings](http://www.ndis-iac.com.au/meetings)



You can ask for help to read our bulletin.

A friend, family member or support person may be able to help you.

## What's in this bulletin?

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## About this Reference Group



A **Reference Group** is a group of people who give us advice about a certain topic.



This Reference Group is about home and living supports.

The Reference Group gives advice to the IAC about how people with disability can:



- live in their own home



- choose where they want to live.

They also give advice to the IAC about how people with disability can:



- do things for themselves in their home



- take part in their community.



The IAC use these ideas from the Reference Group when they write their advice for the National Disability Insurance Agency (NDIA) Board.

We just call them the **NDIA Board**.



The NDIA Board is a group of people who make decisions about all parts of the NDIA.

## The IAC's Principal Member



Ms Leah van Poppel is the IAC's Principal Member.

She is also the Reference Group Co-Chair.

This means she helps run the Reference Group.



Leah thanked members for joining the meeting.



Leah welcomed Ms Samantha Jenkinson to the meeting.



Samantha is the IAC's new Senior Independent Advisor.

This means she supports the IAC to create their advice for the NDIA Board.



Leah explained she will find a new Co-Chair for the Reference Group.



She will do this after the Australian Government shares who the new members of the IAC are.



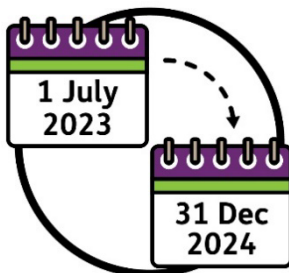
Leah shared the work done since the last meeting by the IAC Reference Group.



This includes the work they did on their Work Plan.

The Work Plan is a document that explains what the Reference Group will work on.

The Reference Group will use this Work Plan from:



- 1 July 2023
- to
- 31 December 2024.

## Our reports



The Reference Group connected with the community to find out about issues that affect them.



The Reference Group members shared these issues with the NDIA.

## What did the reports talk about?

### NDIS plans



Reference Group members worry that people tell older **participants** to leave the NDIS when they have health issues because of their age.



Participants are people with disability who take part in the NDIS.



Members shared that the NDIS have more face-to-face meetings with participants.

And this makes the community happy.

Members also shared that there should be a focus on how home and living supports can help people:



- meet new people



- spend time with family and friends



- take part in their community.



Members explained that some participants have to wait a long time for home and living support.

This means some participants can't get the support they need when they need it.



Members also explained that some people with disability don't apply to the NDIS.

This includes people with disability who live far away from cities and towns.



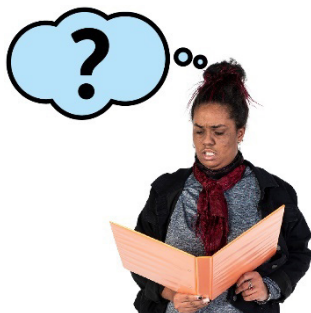
They might not apply to the NDIS because there are not enough **providers** where they live.



Providers support people with disability by delivering a service.



## NDIS services and supports



Reference Group members worry that information about **specialist disability accommodation (SDA)** is hard to understand.



SDA is housing for people with disability who need extra support most of the time.



Members shared that some families don't get the support they need as their child gets older.



For example, some families don't get support to understand how their child can apply to the NDIS.



Some people with disability live on their own.

Members worry that some NDIA staff make them feel like they have to share their home with others.





Members shared that people with **psychosocial disability** should get housing that supports them to do things on their own.

A psychosocial disability affects your mental health.



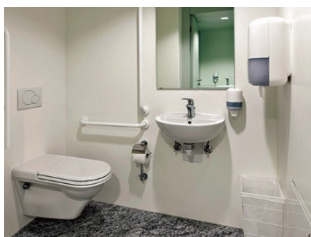
It can affect how you:

- think
- feel
- deal with other people.

For example, housing that gives people with psychosocial disability their own:



- bedroom

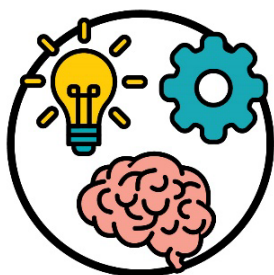


- bathroom



- kitchen area.

An **intellectual disability** affects how you:



- learn new things
- solve problems
- communicate
- do things on your own.



Members explained that some people with intellectual disability don't feel safe in **supported independent living (SIL)** housing.



SIL is help with day-to-day tasks around your home so you can:

- do things for yourself
- learn new skills.



People with intellectual disability should have more support to help them decide:

- where they want to live
- who they want to live with.

## Providers



Reference Group members shared that some providers build **accessible** housing where it suits them.



When housing is accessible it:

- supports what you need
- is easy to move around in.

This might make it harder for people with disability to find a home close to their:



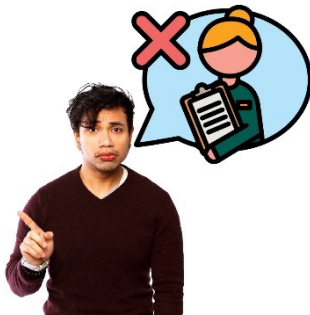
- family



- community.



Members also shared that the NDIS has rules that can make it hard for providers to find people to live in their housing.



Members explained that some providers don't let participants use other providers for SDA supports.



Some providers also keep track of who visits participants.

This makes participants unhappy.

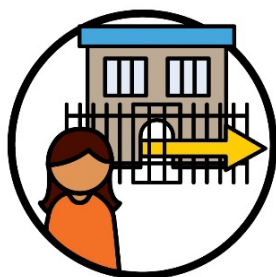


Members worry that some participants don't have choice and control over who they live with in SDA.

## The community and other services



Reference Group members shared that some people with disability find it hard to find a home that meets what they need.



This includes people with disability who leave the **justice system**.

Our justice system includes:



- prisons
- the courts
- police
- the law.



Members explained that the NDIA should work with the health system to support people with disability.



For example, they should work together to support people with disability in **palliative care**.

Palliative care is a support for when you are near the end of your life.



You use palliative care when you have an illness that:

- will get worse
- will last the rest of your life.



Members also explained that the NDIA should support the Australian Government to improve laws about **Special Disability Trusts**.



Special Disability Trusts are set up by the family of a person with disability who needs a lot of support.

They put money into the trust to help pay for future:



- care



- housing.



The Australian Government should improve laws about Special Disability Trusts to support the current cost of housing.



Members shared that some **guardians** chosen by the government don't include people with disability in the decisions they make.

A guardian is a person who acts and makes decisions for you.



Your guardian might be:

- a member of your family
- a friend
- chosen for you by the government.



## Update on NDIA home and living decisions



Mr Ed Duncan gave the Reference Group an update on the NDIA's work to improve home and living decisions.



Reference Group members shared that plans for participants over 65 years old are often the same.



This might mean some older participants don't get the supports they need.



Members worry that some NDIA staff tell older participants to move into **aged care**.

Aged care is where older people live when they can't stay in their home anymore.



Members explained that disability and aged care organisations should work together.





They should work together to understand how the age of a person affects:

- their disability
- the support they need.



Members shared that people with disability should be able to live in their own home for as long as they want.



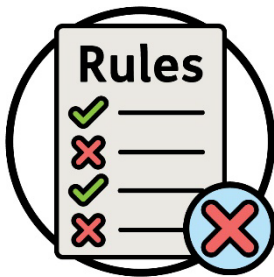
Members also shared that some people with disability need help to use their home and living supports.



For example, people with disability might need support to understand the changes to the cost of SDA.



The NDIA has rules for how long it will take them to make a decision.



Members explained that the NDIA does not always meet these rules when they make decisions about home and living supports.

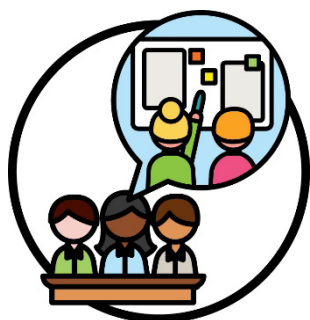


The NDIA need to make sure they support participants while they make decisions.



Members shared that some participants don't feel heard when people make decisions about their home and living supports.

## NDIA co-design projects



IAC Members gave the Reference Group an update about their work on the NDIA's **co-design** projects.



Co-design is when people work together to plan something new.

## What did Dr George Taleporos share?



Dr George Taleporos gave an update about the co-design work for the independent living working group.



Reference Group members shared that 'market' might not be the best word to describe the work that providers do.



They worry that this word will make providers think of people with disability as a chance to make money.



Members also shared that people with disability should have choice and control over where they live.



Some people with disability live in housing that isn't good.

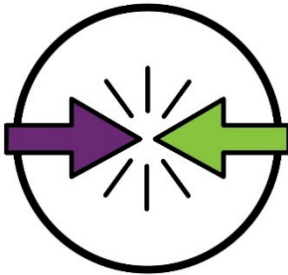


Members explained that the NDIA should support these people to find a better place to live.



Members shared that the community like the idea of a home and living navigator role.

A navigator is a person who connects participants with NDIS supports.



But it's important that the NDIA make sure they manage any **conflicts of interest**.

A conflict of interest is when someone could affect a decision so the result is better for them.

## What did Mr Gavin Burner share?



Mr Gavin Burner gave an update about the co-design work for the better planning working group.



An **NDIS planner** is someone who:

- makes new plans
- changes plans.

Reference Group members shared that the NDIA should support NDIS planners who:



- have experience with different types of disability



- are not **local area coordinators (LACs)**.

An LAC is someone who helps people with disability find and use supports and services.



Members also shared that NDIS planners need more training about **lived experience**.

If you have lived experience of disability, you:



- have a disability
- know what life can be like for people with disability
- can tell your story to help others.

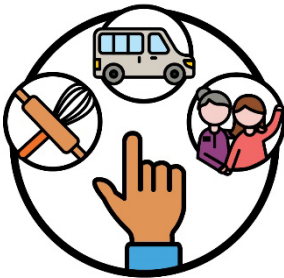


Members explained that NDIS planners should:

- listen to what participants need
- respect what participants need.



And that plan meetings should happen in a place where participants feel comfortable.



NDIS planners should make plans that let participants use their supports in different ways.



**Supported decision-making** is when someone helps you make important decisions about your life and how you will live.





Members also shared that supported decision-making can take time.

This means plan meetings should be longer.



Members explained that the NDIA should share information in ways that participants can understand.

For example, in Easy Read.



Members shared that there should be more support and information about how to:

- manage your own plan
- use your plan.



Members also shared that participants want an easier way for them to contact their NDIS planner.



## Our next meeting



Our next meeting will be in 2024.



You can find out more about our meetings and bulletins on our website.

[www.ndis-iac.com.au/meetings](http://www.ndis-iac.com.au/meetings)

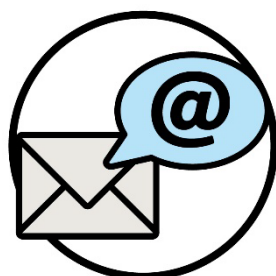
## More information

For more information about this bulletin, please contact us.



You can visit our website.

[www.ndis-iac.com.au](http://www.ndis-iac.com.au)



You can send us an email.

[advisorycouncil@ndis.gov.au](mailto:advisorycouncil@ndis.gov.au)



You can learn more about the NDIS on their website.

[www.ndis.gov.au](http://www.ndis.gov.au)



You can call the NDIS.

**1800 800 110**

## Word list

This list explains what the **bold** words in this document mean.



### **Accessible**

When housing is accessible it:

- supports what you need
- is easy to move around in.



### **Aged care**

Aged care is where older people live when they can't stay in their home anymore.



### **Bulletin**

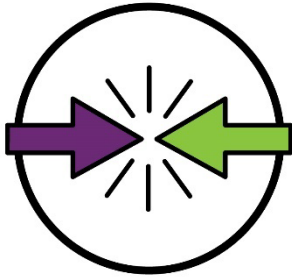
A bulletin is an important news item we share with the community.

It explains what we did in our meeting.



### **Co-design**

Co-design is when people work together to plan something new.



### Conflict of interest

A conflict of interest is when someone could affect a decision so the result is better for them.

### Guardian

A guardian is a person who acts and makes decisions for you.

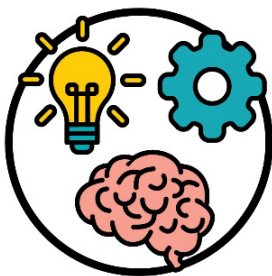


Your guardian might be:

- a member of your family
- a friend
- chosen for you by the government.

### Intellectual disability

An intellectual disability affects how you:



- learn new things
- solve problems
- communicate
- do things on your own.

## Justice system

Our justice system includes:



- prisons
- the courts
- police
- the law.

## Lived experience

If you have lived experience of disability, you:



- have a disability
- know what life can be like for people with disability
- can tell your story to help others.



## Local area coordinators (LACs)

An LAC is someone who helps people with disability find and use supports and services.



## NDIA Board

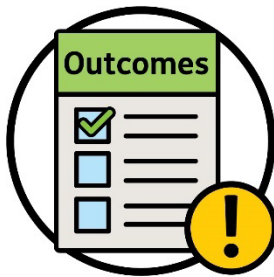
The NDIA Board is a group of people who make decisions about all parts of the NDIA.



## NDIS planner

An NDIA planner is someone who:

- makes new plans
- changes plans.



## Outcomes

Outcomes are important results the NDIA want to get for people with disability.



## Palliative care

Palliative care is a support for when you are near the end of your life.

You use palliative care when you have an illness that:

- will get worse
- will last the rest of your life.



## Participants

Participants are people with disability who take part in the NDIS.



## Providers

Providers support people with disability by delivering a service.

## Psychosocial disability

A psychosocial disability affects your mental health.



It can affect how you:

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- feel
- deal with other people.



## Reference Group

A Reference Group is a group of people who give us advice about a certain topic.



## Special Disability Trusts

Special Disability Trusts are set up by the family of a person with disability who needs a lot of support.



### **Specialist disability accommodation (SDA)**

SDA is housing for people with disability who need extra support most of the time.



### **Supported decision-making**

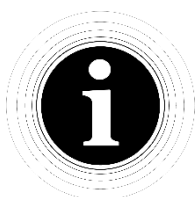
Supported decision-making is when someone helps you make important decisions about your life and how you will live.



### **Supported independent living (SIL)**

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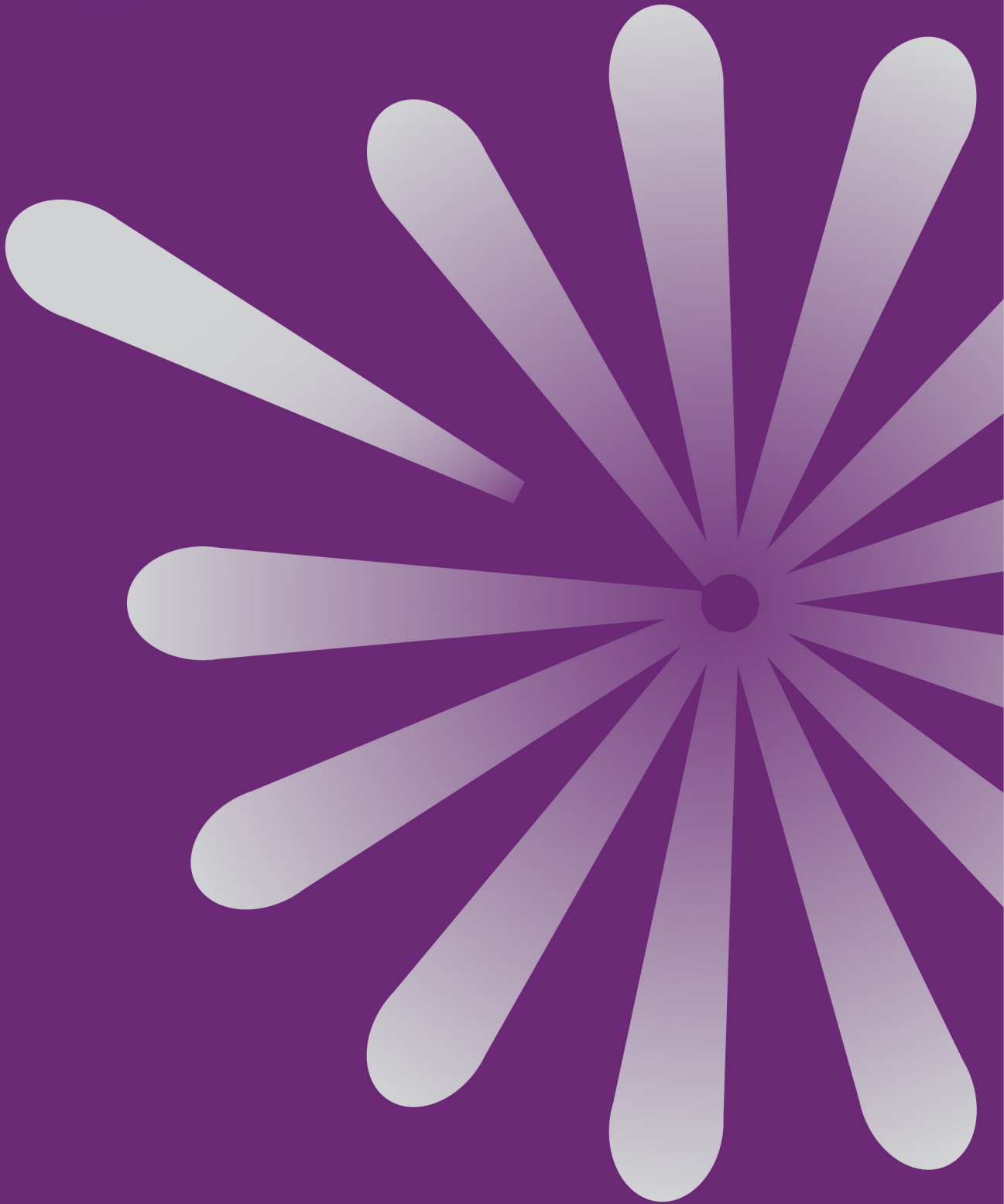


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