

# Children, Young People and Families Reference Group

An Easy Read meeting bulletin

12 October 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**.

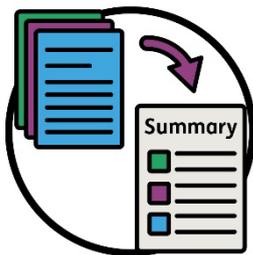
Not bold

This means the letters are thicker and darker.



We explain what these bold words mean.

There is a list of these words on page 35.



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:



- children



- young people



- their families.



The Reference Group shares their ideas with the IAC about how to support children and young people with disability.

This includes support to:



- do things for themselves



- take part in the 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 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.

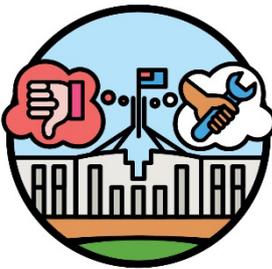


Leah told members that some things may change in the community.



This is because the Disability Royal Commission has shared their ideas.

A **royal commission** is how the government looks into a big problem.



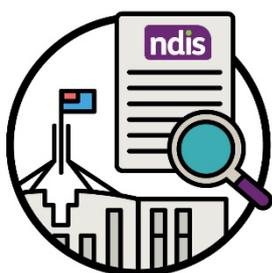
It helps us find out what:

- went wrong
- we can fix.



There will also be change in the community when the **NDIS Review** shares their ideas.

The Australian Government is checking the National Disability Insurance Scheme (NDIS) to find out what:



- works well
- could be better.

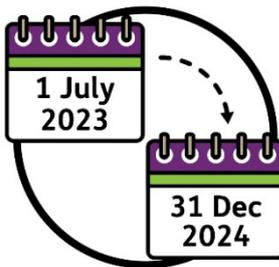
They call it the NDIS Review.



Leah talked about the work the Reference Group has done to make 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.

The IAC will check this Work Plan soon to make sure it supports the work of:



- the IAC



- the Reference Group.

## 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.

## NDIS plans



Reference Group members explained that some people worry about **assessments**.



Assessments help the NDIA work out:

- how your disability affects your life
- what supports you need.

Members worry that some children will not get support when they first need it if:



- assessments cost too much



- it takes too long to get an assessment.



This might mean some children cannot get support when they first need it.

For example, children with **developmental delay**.



Some children might not develop at the same pace as other children of the same age.

They may need extra help to do everyday things.

When this happens, we say they have a developmental delay.



Members shared that **NDIS planners** should change the way they work with families.



An NDIS planner is someone who:

- makes new plans
- changes plans.



For example, they should support people who have experienced **trauma**.



Trauma is the way you feel about something bad that happened to you.

For example, you might feel scared or stressed.

Trauma can affect you for a long time.



This includes families who experience trauma from **child protection** services.

Child protection helps children stay safe.



It is run by the government.

Child protection can decide if a child:

- is not safe in their home
- must live with someone else.



Members worry that some **early childhood partners** don't support families the way they should.

Early childhood partners support:



- children with developmental delay
- children with disability
- their families.

For example, they might not connect families to people or groups who:



- have had the same experiences as them



- can provide support.



Members shared that sometimes the NDIS will check the supports in a child's plan.

But their families thought the NDIS had already agreed to these supports.



Members worry that some families don't make **complaints** about NDIS planners.



When you make a complaint, you tell someone that something:

- has gone wrong
- isn't working well.



Some families think that when they make a complaint it will affect their child's plan.

## NDIS services and supports



Reference Group members worry that families don't know how to find safe **providers** for their children.



Providers support people with disability by delivering a service.



Members worry that some types of **therapy** will stop parents from supporting their child as they grow.



Therapy includes different types of support that can help:

- how you think and feel
- your body to move better.

They also worry that a lot of parents are choosing these therapies instead of ones that:



- are safe



- focus on family support.



Members explained that some **participants** are scared to make a complaint.

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

There should be a way for participants to make a complaint:



- that protects information about who they are



- that is safe for everyone to use.

Members shared that it can be hard to be both:



- a carer of a participant

and



- a participant themselves.



For example, NDIS planners don't always understand how being a carer can affect a carer's disability.

Members also shared that some support workers don't always understand how to:



- work well with young children



- support older children in the way they need.



Members explained that **behaviour support plans** can be hard for some parents to understand.

This means they don't always use these plans the right way.



A behaviour support plan is a document that explains how to support your behaviour.

## The community and other services



Reference Group members explained that some children with disability are not included in schools.

This happens even when they have lots of NDIS support.



State and territory governments should send disability experts to schools.



This might help schools understand how to include students with disability.



Members also explained that students with disability sometimes have less time to:

- learn
- be with other students.



Members shared that the rules for using **accessible** services can make it harder for some people with disability to use them.



When a service is accessible, it is easy to:

- find and use
- understand.



Members also shared they want more information about how the NDIS works with child protection.



This includes what they do to stop the risk of children becoming **homeless** when they turn 18 years old.



People who are homeless don't have a home.

They must find a place to sleep each night.



Members also shared they are happy more people in the community are learning about disability.

This means more people will:



- understand disability



- include people with disability.

## Update on the NDIA Children's Taskforce



The NDIA gave an update about their Children's Taskforce.



The Children's Taskforce will focus on children aged 0-14 years old who take part in the NDIS.

And it will support these children during different stages of their life.



Reference Group members shared that there are long wait times for early childhood partners.

This means some families decide to go somewhere else for advice.



Members worry about how many families only want to use services and supports with NDIS **funding**.



Funding is the money from your plan that pays for the supports and services you need.



Some families choose these services instead of supports outside of the NDIS that might be better for their child.

Members explained that medical advice guides people to make decisions about children with:



- disability



- developmental delay.



But medical advice doesn't support families to understand disability.



The NDIS Early Supports program is important to help parents understand more about:

- disability
- developmental delay.



It is also important to help parents build their skills to support their child.



Members shared that participants need more support when they manage their own plan.



Some families don't know that it is a lot of work to manage your own plan.



Members also shared that the NDIA should use **co-design** to understand how they should give information to families.



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



Members are happy with the co-design work the Children's Taskforce has done.



This includes their work to make resources for early childhood teachers.



These resources aim to support teachers who work with children with:

- disability
- developmental delay.



The resources can help them to understand and include these children.

# Thoughts on the Disability Royal Commission



The Disability Royal Commission shared their ideas on 29 September 2023.

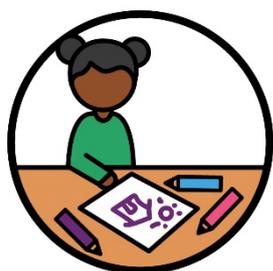


Reference Group members shared that some things were missing from the Disability Royal Commission's final report.

They include:



- transport



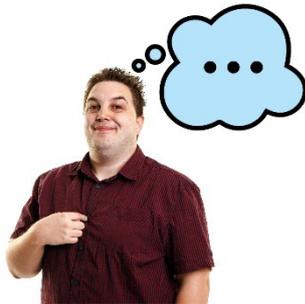
- early childhood education



- support for people with disability after they leave school.



Members explained that some of the words used in the report might create bad **attitudes** about disability.



Your attitude is what you think, feel and believe.



Members talked about the Disability Royal Commission's ideas on work that people with disability can do.



For example, how **volunteer** work can support people with disability to find paid work.



When you volunteer, you:

- work but you don't get paid.
- do work that helps other people.

Members shared that the Disability Royal Commission's ideas will:

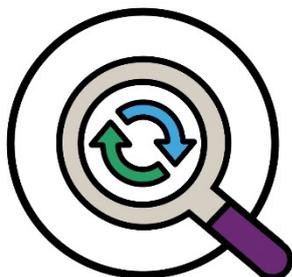


- include a lot of hard work



- take a long time to finish.

## Update on Reforms for Outcomes



Ms Sylvana Mahmic and Ms Skye Kakoschke-Moore gave the Reference Group an update about their work on the Reform for Outcomes.



The Reform for Outcomes will focus on the changes the NDIA can make to support better **outcomes**.

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



Reference Group members shared that there should be more NDIS planners who understand children and families.



Members also shared that the NDIA should collect information on the skills of their planners.

This means they can find out what training NDIS planners need.



Members explained that the NDIA should focus on how to keep good staff.



Members shared that the NDIA should hire training organisations run by people with disability.

This would give NDIA staff the chance to:



- ask questions



- learn from people with disability.



Members explained that plans should be **flexible** for some changes.

When plans are flexible, it means you can use them in different ways.



For example, when a person starts or leaves school.

Members also explained that flexible plans should let participants:



- move their funding to different supports



- choose certain areas of their plan to check.

Members shared that flexible plans are important for participants when:



- a big change happens in their life



- something bad happens to them.



For example, if a participant experiences **domestic and family violence**.

Domestic and family violence is when someone close to you hurts you.

This could be:



- someone you have or had a relationship with
- a member of your family.

## 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 visit the NDIS 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 a service is accessible, it is easy to:

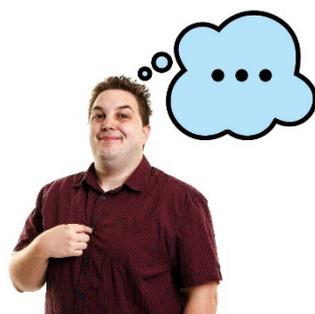
- find and use
- understand.



### **Assessment**

Assessments help the NDIA work out:

- how your disability affects your life
- what supports you need.



### **Attitude**

Your attitude is what you think, feel and believe.



### **Behaviour support plan**

A behaviour support plan is a document that explains how to support your behaviour.



## Bulletin

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

It explains what we did in our meeting.



## Child protection

Child protection helps children stay safe.

It is run by the government.

Child protection can decide if a child:

- is not safe in their home
- must live with someone else.



## Co-design

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



## Complaint

When you make a complaint, you tell someone that something:

- has gone wrong
- isn't working well.

## Developmental delay



Some children might not develop at the same pace as other children of the same age.

They may need extra help to do everyday things.

When this happens, we say they have a developmental delay.

## Domestic and family violence

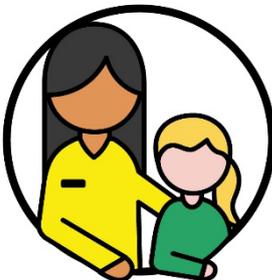


Domestic and family violence is when someone close to you hurts you.

This could be:

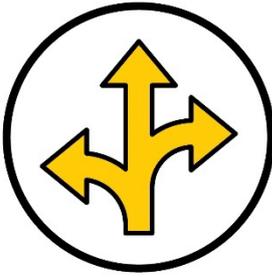
- someone you have or had a relationship with
- a member of your family.

## Early childhood partners



Early childhood partners support:

- children with developmental delay
- children with disability
- their families.



### Flexible

When plans are flexible, it means you can use them in different ways.



### Funding

Funding is the money from your plan that pays for the supports and services you need.



### Homeless

People who are homeless don't have a home. They must find a place to sleep each night.



### NDIA Board

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



### NDIS planner

An NDIS planner is someone who:

- makes new plans
- changes plans.

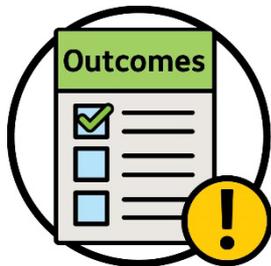
## NDIS Review



The Australian Government is checking the NDIS to find out what:

- works well
- could be better.

They call it the NDIS Review.



## Outcomes

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



## Participants

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



## Provider

Providers support people with disability by delivering a service.



## Reference Group

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



## Royal commission

A royal commission is how the government looks into a big problem.

It helps us find out what:

- went wrong
- we can fix.



## Therapy

Therapy includes different types of support that can help:

- how you think and feel
- your body to move better.

## Trauma



Trauma is the way you feel about something bad that happened to you.

For example, you might feel scared or stressed.

Trauma can affect you for a long time.

## Volunteer



When you volunteer, you:

- work but you don't get paid.
- do work that helps other people.



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