



# Children, young people and families Reference Group

An Easy Read meeting bulletin

13 September 2022



## How to use this bulletin



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

It explains what we did in our last meeting.

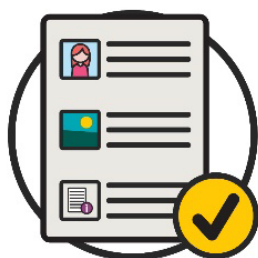


The Independent Advisory Council gives advice about ways to make the NDIS better.



The Council wrote this bulletin.

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



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**.

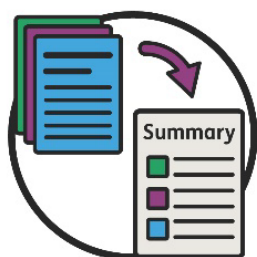
# Not bold

This means the letters are thicker and darker.



We explain what these bold words mean.

There is a list of these words on page 25.



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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## What is this Reference Group about?



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 gives advice to the Council about how to support children and young people with disability.

This includes support to:



- do things for themselves



- take part in the community.

## A message from the Council's Principal Member



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

She is also the Reference Group Co-Chair.

This means she helps run the Reference Group.



Leah shared that the work the Reference Group has done since their last meeting will help them give advice to the NDIA.



This advice will focus on helping children and young people speak up about NDIS supports.



It will also give the NDIA new ideas about how to support and listen to children and young people.

# Making advice better for children and young people



Leah asked the Reference Group for advice about how the NDIA can listen to what children and young people have to say.



The Reference Group said the NDIA needs to support children and young people to have their own voice.

They said it's important to listen to children and young people who have different:



- ages
- disabilities
- needs.



They also said the Reference Group needs to include children and young people when they make the advice.

This includes children and young people who don't use words or speech to communicate.

The Reference Group said we also need to include children and young people as members of:



- the Council



- it's Reference Groups



- the NDIA's Participant Reference Group.

They said the NDIA should think about writing a new document about how they will:



- work with children and young people
- listen to the voices of children and young people.





The Reference Group said information the NDIA shares with the community should include children and young people being themselves.

And the NDIA shouldn't have adults speaking for them.



They said it's important to think about how the **NDIS Quality and Safeguards Commission (NDIS Commission)** can help with this work.

The NDIS Commission makes sure people with disability who take part in the NDIS:

- are safe
- get good services.



They also said it's important for the NDIS Commission to make sure children and young people receive good services.

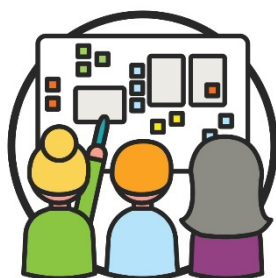
# Updates on the work we are doing with the community

## The NDIA's co-design work

The Reference Group learned about:



- how the NDIA are working with the community



- different **co-design** projects.



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

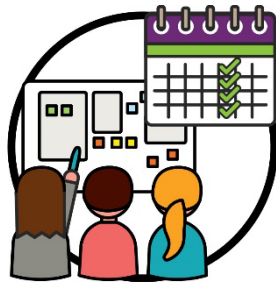


This included ways the NDIA are working with children and young people on co-design.



The Reference Group shared that the NDIA should think about risks children and young people face when they make sure **participants** are safe.

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



The Reference Group also asked for regular updates about the NDIA's co-design projects.



And they shared that the NDIA could think about using Victoria's Youth Strategy 2022–2027 in their co-design work.

This document explains how the Victorian Government will work with young people.

## What the disability community are doing

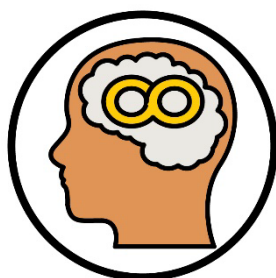


The Reference Group learned about how the disability community are speaking up for children and young people.

This included work by an organisation called Autism CRC.

They are making a guide to support children with **autism** in Australia.

Autism affects how you:

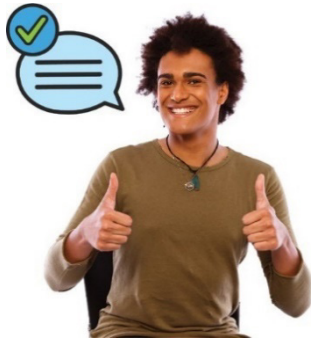


- think
- feel
- communicate
- connect and deal with others.

The Reference Group shared that it's important to have rules about the difference between a child:

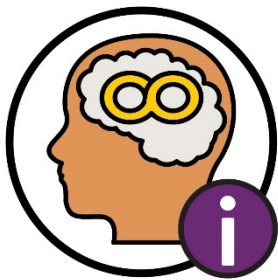


- agreeing to something
- and
- giving **informed consent**.



When you give informed consent, you:

- say it's okay to do something
- understand what you are agreeing to.



They shared that there needs to be more information about supports for people with autism.

This includes support about how to find a job.



The Reference Group also shared important things that affect how children develop.

This includes:

- taking part in the community
- being included.



They shared that this is important for children with disability at school.

## What CYDA are doing



The Reference Group learned about the work Children and Young People with Disability Australia (CYDA) are doing.

CYDA is an organisation for children and young people with disability.

This includes how CYDA:



- supports children and young people to speak up about things that affect them
- include them in co-design projects and keep them safe.



The Reference Group shared that organisations need to create safe spaces for children and young people who are different ages.

These safe spaces will help them take part and share their ideas.



They also shared that the NDIA needs to think about ways to include children and young people who don't use words or speech to communicate.



And that it's important to use co-design in different ways when working with children and young people.

For example, using images.



The Reference Group also shared that organisations should pay young people who:

- are old enough to work
- take part in co-design projects.

## Our reports



Our Reference Group connect with the community to find out about issues that affect them.



Our Reference Group Members shared these issues with the NDIA.

## What did the reports talk about?

### Support to find a job



Young people with disability need support to find and keep a job.



And they want support for when they move from:

- learning and training
- to
- work.



## NDIS plans

There are some participants who:



- are deaf or don't hear very well



- travel a lot.



It's hard for them to use the supports in their NDIS plan.

And they don't use their plans as much.

Participants also face challenges with plan **reviews**.



When you review something, you check to see what:

- works well
- can be better.



This includes participants getting less **funding** and supports in their NDIS plan.

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



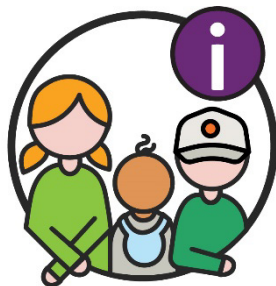
When children younger than 7 have a plan, their family doesn't get much support to manage their plan.



**Local Area Coordinators (LACs)** don't provide enough support for children and their families.

LACs are people who support people with disability when they take part in the NDIS.

## Sharing information with the community



The NDIA should publish information that includes children.



It's important to let people know about how they are changing how young children get support early in their lives.

We call it the early childhood approach.

## Pricing changes that affect participants



Some businesses and **providers** aren't doing the right thing when they charge people for services.

Providers support other people by delivering a service.



This includes charging people more money when they find out people are participants.

## Partners in the Community (PITC) program



The way organisations apply to take part in the **Partners in the Community (PITC)** program has stopped.

PITC are community organisations the NDIA works with to support participants.

People are worried this might be a problem because the PITC program provides:



- services for young children



- LAC services.

And they worry that if new businesses can't apply for the PITC program, it will affect how they:

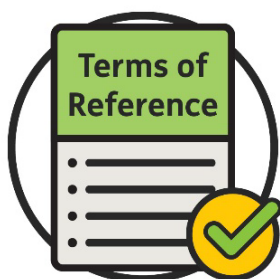


- find new staff to work
- promise that people's jobs will last a long time.

## Reviewing the NDIS



The government wants to review the NDIS to check how well it supports participants.



Leah explained that governments haven't agreed on the **terms of reference** yet.

The terms of reference is a list of things governments want to focus on.



She shared that disability ministers have agreed that governments should review:

- how the NDIS works
- the way the NDIS does things
- the future of the NDIS.

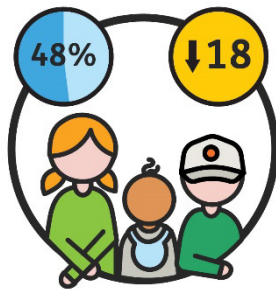


Disability ministers also agreed this includes focusing on having:

- good services and workers
- more services and workers.



The Reference Group explained that the terms of reference should include children and young people.

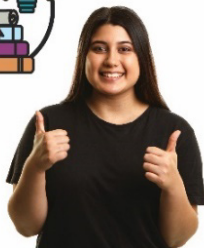


48% of all participants are people aged 18 years old or younger.

So it's important to think about how the NDIS supports them.



They also shared that the people in charge of reviewing the NDIS need to understand what younger participants need.



This includes having the right:

- information
- skills.

## Our next meeting



Our next meeting is in 2023.



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**

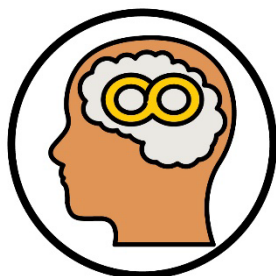


## Word list

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

### Autism

Autism affects how you:



- think
- feel
- communicate
- connect and deal with others.

### Bulletin

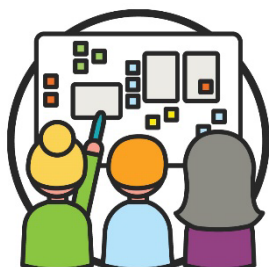
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### Co-design

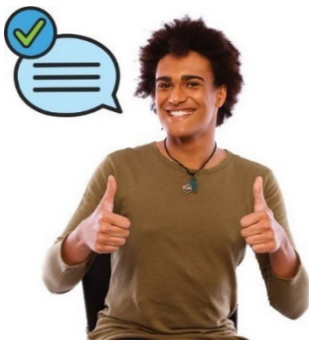
Co-design is when people work together to plan something new.





## Funding

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



## Informed consent

When you give informed consent, you:

- say it's okay to do something
- understand what you are agreeing to.



## Local Area Coordinators (LACs)

LACs are people who support people with disability when they take part in the NDIS.



## NDIS Quality and Safeguards Commission

The NDIS Commission) makes sure people with disability who take part in the NDIS:

- are safe
- get good services.



## Participants

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



## Partners in the Community (PITC)

PITCs are community organisations the NDIA works with to support participants.



## Providers

Providers support other people by delivering a service.



## Reference Group

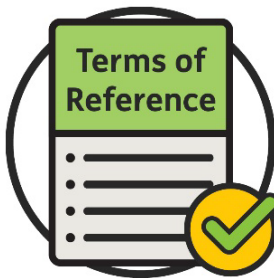
A Reference Group is a group of people who give us advice about a certain topic.

## Reviews



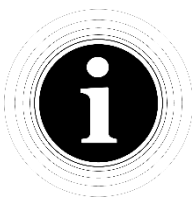
When you review something, you check to see what:

- works well
- can be better.



## Terms of reference

The terms of reference is a list of things the NDIA want to focus on.



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to the **ndis**



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