

Children, young people and families Reference Group

An Easy Read meeting bulletin

27 February 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 last meeting.

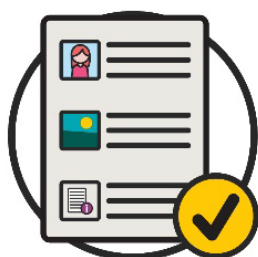


The Independent Advisory Council gives advice about ways to make the NDIS better.



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 28.



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



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?

What is this Reference Group about? 5

The Council's Principal Member 7

The NDIS review 8

Our advice about listening to children and young people 11

The NDIA's early childhood approach 13

Our reports 16

Our next meeting 26

More information 27

Word list 28

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.

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 talked about the work the Reference Group has done since their last meeting.

The NDIS review



The Australian Government will **review** the NDIS.

When the Australian Government reviews the NDIS, they check to see what:



- works well



- could be better.



We call this the NDIS review.

The Reference Group talked about:



- ways the Council should work with the NDIS review



- what the NDIS review needs to look at.



Reference Group members want to work with the NDIS review on issues for children and young people.

They want to know if the NDIS review will talk to:



- children and young people



- their families.

They think the NDIS review should think about:



- the Council's advice



- what the Reference Group members say.



Reference Group members were happy the NDIS review will start using some new ideas.



They also explained the NDIS review should make its reports clear.

Our advice about listening to children and young people



We wrote some advice to share with the NDIA about listening to children and young people.



We called our advice:

‘Improving the NDIS for children and young people – the importance of being guided by their voice’.



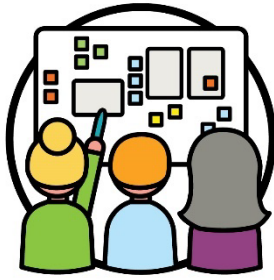
Reference Group members shared their ideas about our advice.



They told us our advice will help the NDIA support children and young people.

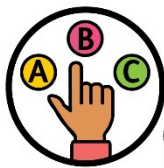


But they think the NDIA should be careful when they change things.



They told us our advice should explain how important **co-design** is.

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



They also told us our advice should explain what **parental agency** means.

Parental agency is about what choices and decisions a parent can make for their child.



Our advice should also help children and young people with disability who can't talk to have their say.



Reference Group members want to know more about the NDIA's new Children's Taskforce.

The NDIA's early childhood approach



The Reference Group learned about how the NDIA are changing how young children get support early in their lives.

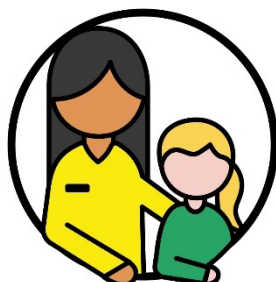
We call it the early childhood approach.



They are happy with how the NDIA shares information about the early childhood approach.



Reference Group members explained the NDIA has the chance to make **early childhood partners** better.



Early childhood partners support young children early in their lives.

These organisations work with the NDIA.

They can do this by:



- using research



- agreeing on a best way to do things



- working together.

They explained the NDIA need to look at how the early childhood approach works in places:



- far away from cities and towns



- where there are no early childhood partners.



They worry that there are not enough supports for children who leave the NDIS.

Our reports

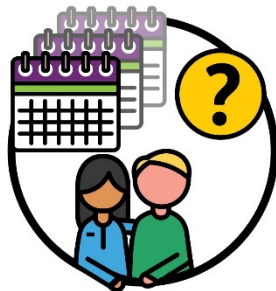


Our Reference Group connect with the community to find out about issues that affect them.



Our Reference Group Members shared these issues with the NDIA.

Who can use the NDIS

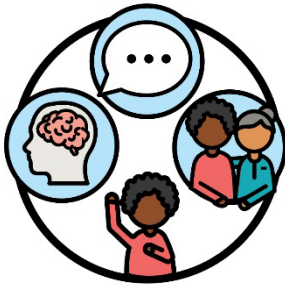


Reference Group members shared that families have to wait a long time to find out what support they can get.



Some families of children with **autism** have to wait up to 3 years.

Autism affects how you:



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



Reference Group members worry that when families have to wait a long time, it can affect how children develop.



And sometimes other parts of the government have to step in, like the courts and law.

This can happen when families don't have the support they need.



Reference Group members shared that some organisations charge more because so many people are waiting for these services.

This is not fair.



Reference Group members explained the community wants to know if people with **fetal alcohol spectrum disorder (FASD)** can use the NDIS.



Drinking alcohol while pregnant can cause FASD. It affects how a baby grows before it's born.



The community also want to know how many **participants** have FASD.

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

NDIS plans



Reference Group members shared that sometimes the NDIA doesn't tell participants why they get less **funding** in their NDIS plan.



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

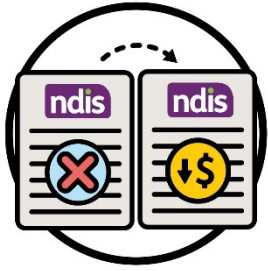
Some families worry they will get less funding if they tell the NDIA their child:



- needs more support



- is doing well.



They also worry they will get less funding if they don't use it all.



But sometimes families have to wait too long because there aren't enough services where they live.



Reference Group members explained families worry about:

- what **parental responsibility** means
- how it relates to the NDIS.



Parental responsibility is what tasks parents must do for their children.

This includes what decisions they can make for them.



Families want better information about their children's NDIS plans.

This includes information about how to use their supports.



Some people think families should get **support coordination** for their first NDIS plan.

Support coordination helps you manage the supports and services in your plan.



Reference Group members also shared it can be hard for families to get funding for their child when:

- someone else helps to care for the child
but
- there is no legal agreement that says they do this.

Providers

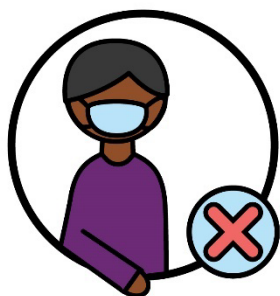


Providers support people with disability by delivering a service.



Reference Group members explained that providers should support young people to find and keep a job when they finish school.

And the NDIA should do more to make sure providers support them.



They also explained some support workers won't wear a mask when they work with participants who are at risk.



The NDIS Quality and Safeguards Commission (NDIS Commission) makes sure people with disability who take part in the NDIS:

- are safe
- get good services.

Reference Group members shared that sometimes the NDIS Commission does not help people when they tell them something:



- went wrong



- could be better.

The community



Reference Group members shared that families want the NDIS review to support children and young people to have their say.



They also explained that parents of children and young people with disability might need mental health support.



Autism CRC is an organisation.

They do research on autism all around Australia.

Autism CRC shared guidelines about how to support:



- children and young people with autism



- their families.



You can read the guidelines on the Autism CRC website.

www.autismcrc.com.au/news/latest-news/australias-first-national-guideline-supporting-learning-participation-and

Our next meeting



Our next meeting is 11 May 2023.



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

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



You can send us an email.

advisorycouncil@ndis.gov.au



You can visit the NDIS website.

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:

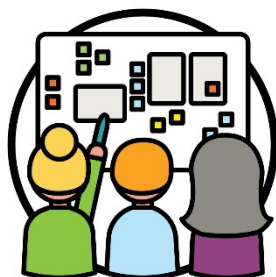
- think
- feel
- communicate
- connect and deal with others.



Bulletin

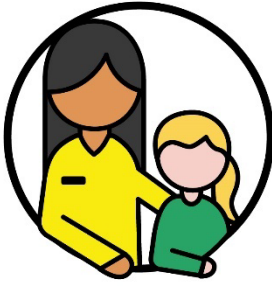
A bulletin is an important news item we share with the community.

It explains what we did in our last meeting.



Co-design

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



Early childhood partners

Early childhood partners support young children early in their lives.

These organisations work with the NDIA.



Fetal alcohol spectrum disorder (FASD)

Drinking alcohol while pregnant can cause FASD.

It affects how a baby grows before it's born.



Funding

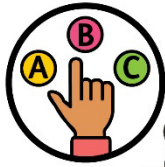
Funding is the money from your plan that pays for the supports and services you need.



NDIS Quality and Safeguards Commission

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

- are safe
- get good services.



Parental agency

Parental agency is about what choices and decisions a parent can make for their child.

Parental responsibility



Parental responsibility is what tasks parents must do for their children.

This includes what decisions they can make for them.



Participants

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



Providers

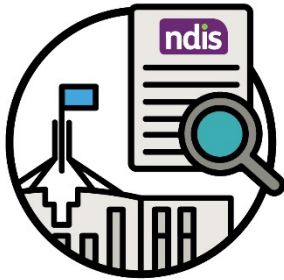
Providers support people with disability by delivering a service.



Reference Group

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

Reviews



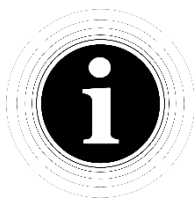
When the Australian Government reviews the NDIS, they check to see what:

- works well
- could be better



Support coordination

Support coordination helps you manage the supports and services in your plan.



The Information Access Group created this Easy Read document using stock photography and custom images. The images may not be reused without permission. For any enquiries about the images, please visit www.informationaccessgroup.com. Quote job number 4773-B.



**Independent
Advisory
Council**
to the **ndis**



ndis-iac.com.au