



Children, young people and families Reference Group

An Easy Read meeting bulletin

02 August 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.



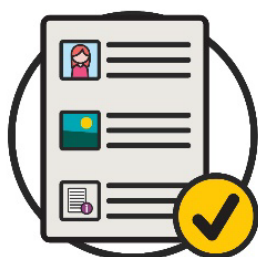
The Independent Advisory Council gives advice about ways to make the NDIS better.

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 30.



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 IAC's Principal Member 7

Our reports 9

Our Reference Group Work Plan 19

Update on the NDIS Review 23

Update on the Early Years Strategy 27

Our next meeting 28

More information 29

Word list 30

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 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 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



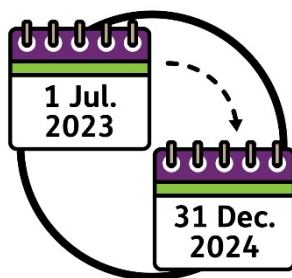
Ms Leah van Poppel is the IAC's Principal Member.

She is also the Reference Group Co-Chair.

This means she helps run the Reference Group.



Leah welcomed old and new members to the Reference Group.



Members will work with the Reference Group from:

- 1 July 2023
- to
- 31 December 2024.



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



She will do this after the **Minister** for the National Disability Insurance Scheme (NDIS) shares who the new members of the IAC are.

A minister leads an area of the government.

Leah shared the work done since the last meeting by:



- the IAC



- the IAC Reference Group.



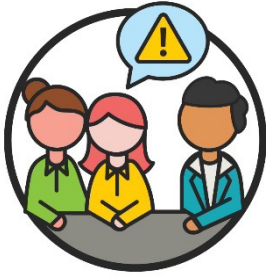
This includes their work on their advice for the NDIA.

It's called *Improving the NDIS for children and young people: the importance of being guided by their voice.*



The IAC are waiting for the NDIA to share their thoughts about what they will do to support the advice.

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 parents worry their child's NDIS plan will change when they have planning meetings.



The NDIS should tell parents before meetings that they can use the same plan if their child doesn't need new supports.



This might mean that parents will spend less money on **assessments**.

Assessments help the NDIA work out:

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



Members also explained that some families can experience **trauma** from planning meetings.



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.

NDIS services and supports



Reference Group members shared that some families have to use a lot of their **funding** on assessments.

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



They do this to get proof that their child with disability needs long-term support from the NDIS.

This means that:



- children might not get the right amount of support they need



- families focus on what their child can't do and not on what they are good at.



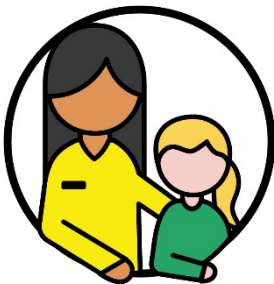
It can also mean that some health care services are too busy with assessments.

And can't provide as much support as they should.



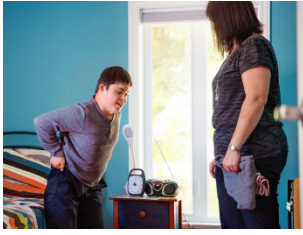
Members shared that the NDIS need to look at how preschools can be a good place for children to get NDIS supports.

For example, they should look at how preschools can connect families with **early childhood partners**.



Early childhood partners support:

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



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 explained that the NDIS should do more to support young **participants** as they become adults.

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

This includes supporting participants to:



- do more tasks on their own



- take part in activities with other people



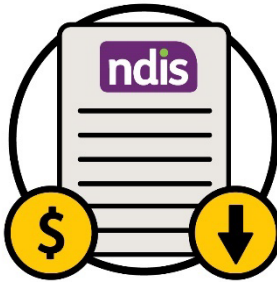
- find support workers who are not their parents.



The NDIS should focus on providing this support to young people who come from different backgrounds.



Members shared that some people tell young people with disability not to work until they leave high school.



Members also shared that some young people with disability lose funding when they leave school.

This might make life harder for young people who need supports as they become an adult.



Members explained that some young people don't have much choice in what supports they get.

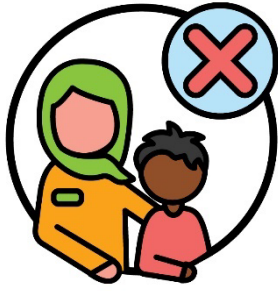


For example, young people who need support and want to live on their own.



Members also explained that some young people with disability feel upset over not having more choice and control about their supports.

And because of this they don't use their supports.



Young people with disability can lose their supports if they don't use them.

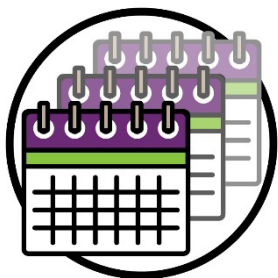
And it can be hard to get these supports back.



Members shared that it can be hard to find an **occupational therapist** in some states.



An occupational therapist helps someone find ways to do everyday tasks.



This means some participants have to wait longer to get the support they need.

The community and other services



Reference Group members shared that there should be NDIS supports for children to use at school.

Supports work better for children when they're in a place they know well.



Members explained that the NDIS should work more closely with other services to help children and young people get the support they need.

For example, working with the **justice system**.

Our justice system includes:



- prisons
- the courts
- police
- the law.



Members shared that there are not as many chances for young people with disability to connect with people their own age.



This can affect young people with disability who live far away from cities and towns more than other people.



Members shared that more people in the community should understand and use **early intervention**.



Early intervention is when people get services and support:

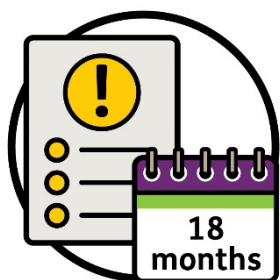
- as early as possible in their lives
- when they first get a disability.



This includes making sure parents and families:

- know their job in early intervention
- have support to speak for their child.

Our Reference Group Work Plan



Reference Group members discussed what **priorities** they should focus on over the next 18 months.

Our priorities are things we think are very important.



We will use these priorities to make a Work Plan.

This Work Plan will guide the Reference Group's advice to the IAC.



Members agreed on what these priorities should be and what work they will focus on.



Members explained that they will include **intersectionality** in their work.



You can be different in more than one way.

And people might treat you differently for each part of who you are.

We call this intersectionality.



Members also shared that the NDIA need an **advisory group** for young people.

And this group should include members that are young people.



An advisory group is a group of people who work with the NDIA to share what:

- is working well
- needs to work better.

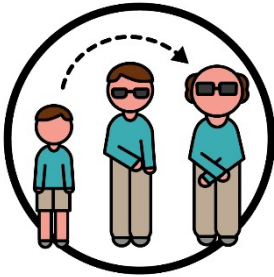


Members explained they will focus on ways to better support families and children with disability.

This includes:



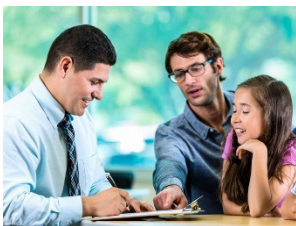
- more education for parents and families



- supporting children and young people as they grow older



- making sure children can get the NDIS supports they need early in their lives.

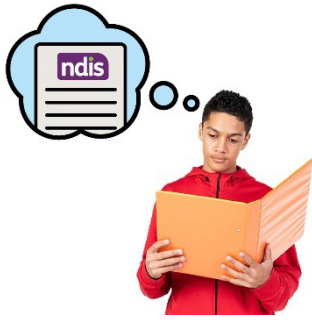


And they will also focus on making sure children and families get good supports.

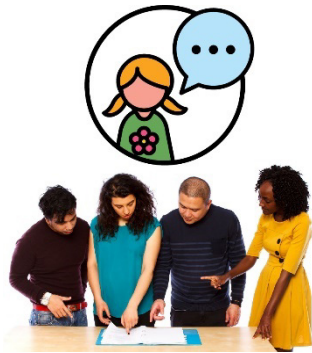
Members explained they will look at ways to support young people with disability to:



- make their own decisions
- do things on their own.



For example, teaching young people with disability how to use their NDIS plan before they turn 18 years old.



Members shared that the NDIA should think about what young people have to say when they make NDIS plans.



Members explained they will focus on how they will work with children and young people.

This is so we can use the experiences of children and young people to support the work we do.

Members also explained how they will focus on important areas in:

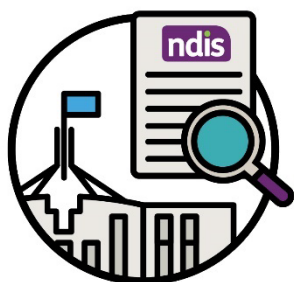


- the community



- other government services.

Update on the NDIS Review



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

- works well
- could be better.

They call it the **NDIS Review**.



Professor Bruce Bonyhady AM shared an update on the NDIS Review.

He is the NDIS Review Co-Chair.

This means he helps run the NDIS Review.



Bruce discussed the NDIS Review's report on what they've heard from the community.

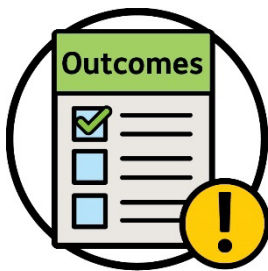


He also asked the Reference Group how the NDIS could fix issues for:

- children and young people
- their families.

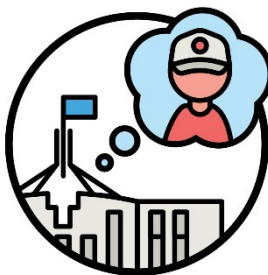


Reference Group members shared that the NDIA should improve what the community knows about the goals of the NDIS.



For example, how the NDIS creates better **outcomes** for people.

Outcomes are important results we want to achieve.



Members explained that the government should think more about what young people with disability need.

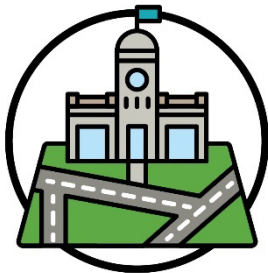


This includes young people with disability who need more support to find housing.

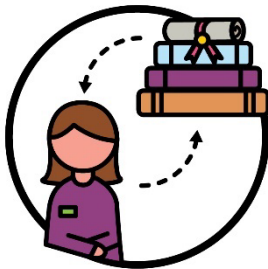
Members also explained that there should be more community supports and programs from:



- states and territories



- local governments.



Members shared that the NDIS should find better ways to work with other government services.

For example, education services.



People want the NDIA to offer NDIS supports in schools so that children with disability can still take part at school.



Members also shared that the NDIS's plan to support children should also support young people as they become adults.



This can help the NDIS understand what young people need when they become adults.



Children have better outcomes when they get supports early in their life.



This might be why there are more children taking part in the NDIS than ever before.



Members explained that the NDIA should not look at this as a bad thing.

And that some participants feel like it's their fault that the NDIS costs more than what the government thought it would.



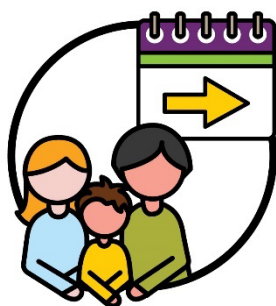
Members shared that the NDIA doesn't always make the same decisions about NDIS supports.

Update on the Early Years Strategy



The Department of Social Services (DSS) shared an update about their Early Years Strategy.

In this bulletin we just call it the strategy.



The strategy is a plan for how the Australian Government will work to support children and their families in the future.



Reference Group members shared that people with disability and their community should have more say on the strategy.

Our next meeting



Our next meeting is 12 October 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.



Advisory group

An advisory group is a group of people who work with the NDIA to share what:

- is working well
- needs to work better.



Assessment

Assessments help the NDIA work out:

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

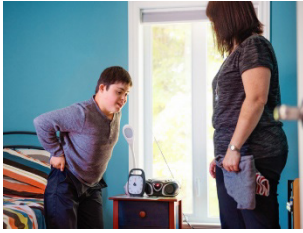


Bulletin

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

It explains what we did in our last meeting.

Developmental delay

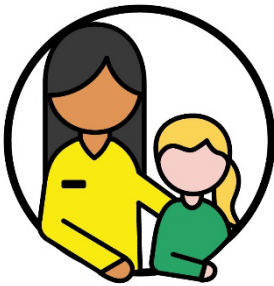


Some children might not develop at the same pace as other children of the same age.

They may need extra help to do everyday things.

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

Early childhood partners



Early childhood partners support:

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

Early intervention



Early intervention is when people get services and support:

- as early as possible in their lives
- when they first get a disability.



Funding

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



Intersectionality

You can be different in more than one way.

And people might treat you differently for each part of who you are.

We call this intersectionality.



Justice system

Our justice system includes:

- prisons
- the courts
- police
- the law.



Minister

A minister leads an area of the government.



NDIA Board

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



NDIS Review

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

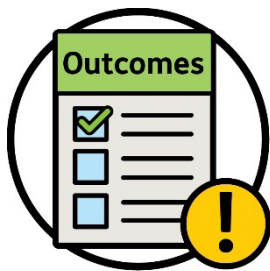
- works well
- could be better.

They call it the NDIS Review.



Occupational therapist

An occupational therapist helps someone find ways to do everyday tasks.



Outcomes

Outcomes are important results we want to achieve.



Participants

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



Priorities

Our priorities are things we think are very important.



Reference Group

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

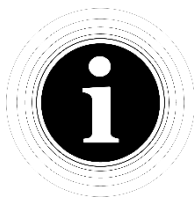


Trauma

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.



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 5264-B.



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



ndis-iac.com.au