Research Report

A framework for supported decision-making

Easy Read version
How to use this report

The Living with Disability Research Centre is part of the La Trobe University.

They:

- did some research
- wrote this report for the Disability Royal Commission (the Royal Commission).

When you see the word ‘we’, it means the Royal Commission.

We wrote this report in an easy to read way.

We use pictures to explain some ideas.

We wrote some important words in **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 32.
This Easy Read report is a summary of a report called *Diversity, dignity, equity and best practice: a framework for supported decision-making*. A summary only includes the most important ideas.

You can find the other report on our website.


You can ask for help to read this report. A friend, family member or support person may be able to help you.
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What is this report about?

A group of people did research on supported decision-making.

They wanted to find out:

- what supported decision-making is
- how we can make sure everyone can get support to make their own decisions.

They also wanted to find out how important supported decision-making is for people with cognitive disability.

A cognitive disability affects how people:

- think
- communicate
- understand
- focus on what they’re doing
- remember.
There are different types of cognitive disability, including:

- intellectual disability
- acquired brain injury
- mental health conditions
- dementia.

As part of their research, the group of people read all the research we already have about supported decision-making.
They also asked 77 people to share their ideas with them.

Those people included:

- people with cognitive disability
- their families and carers
- advocates – people who support people with disability to have their say
- service providers – organisations that deliver a service to people with disability.
This research helped them work out what should be in a **framework** for supported decision-making.

A framework is a plan for how things should work.

The framework should make sure people with cognitive disability can get support to make their own decisions.

This report explains what:

- good supported decision-making is
- should be in the framework.
What is supported decision-making?

Supported decision-making is when a person with cognitive disability gets support to make their own decisions.

A supporter is someone who helps them:

- understand their choices
- think about what they want.

A supporter also helps them to think about what may happen because of a decision they make.
Many people talk about supported decision-making.

But sometimes they think it means different things.

This can be very confusing.

There are 2 ways that people approach supported decision-making.
Binary approach

The binary approach has two parts:

• supported decision-making

• substitute decision-making.

It focuses on supported decision-making first.

But when a person can’t take part in decision-making, they are left out.
They might not be able to make their own decisions because they have trouble:

- understanding their choices
- explaining what they want.

When this happens, someone else will make the decision for them.
We call this person a substitute decision-maker.

The substitute decision-maker will make a decision based on what other people think is best.

This means the person with cognitive disability is left out of supported decision-making.
Principled approach

The principled approach makes sure no one is left out of supported decision-making.

If a person has trouble saying what they want, they:

- are not left out
- get the support they need to take part in decision-making.

Supporters will try to understand what the person wants.

Supporters will:

- get to know them well
- spend time with them
- talk to other people who know them.
If supporters make a decision for the person, they will base it on what they think the person wants.

This approach works for most types of decisions.

**Taking risks**

Sometimes decisions involve risk.
This means we don’t know what might happen.

Taking a risk might mean the person has a good new experience.
Or they might get hurt.
The principled approach says that it’s good for people to choose what risks they want to take.

But people shouldn’t use supported decision-making if a person wants to do something that will really hurt them.

When this happens, someone else will make the decision for the person.

They will find a way to do what the person wants without them getting hurt.
Why is supported decision-making important?

What a person wants is always the focus of supported decision-making.

Supported decision-making helps people with cognitive disability to:

• connect with other people

• know their rights.

Rights are rules about how everyone should be treated fairly and equally.

It also shows the world that people with cognitive disability can make their own decisions about their lives.
Supported decision-making only works if people with cognitive disability have supporters to help them.

Supporters can be people who aren’t paid to support someone.

For example, a family member or friend.

Supporters can also be people who are paid to support someone as part of their job.

For example, a carer or support person.

It’s good for a person with cognitive disability to have:

- more than one supporter
- unpaid supporters.
But many people don’t have unpaid supporters. This means they need to rely on paid supporters.

It can be hard for paid supporters to provide good support.

Paid supporters need to think about other things that affect the decision, including:

- their job
- what the person who hired them wants
- what the person with cognitive disability wants.
Important ideas for the framework

We think the framework should be a guide. It should make sure all people with cognitive disability can get supported decision-making.

It shouldn’t matter:

• where they are

• what decision they are making.

We think the framework should include 9 principles for supported decision-making.

Principles are important ideas we should always think about.
1. All adults have the right to make decisions about their lives.

2. Everyone should get the support they need to make decisions.

3. What a person wants should be the focus of all decisions.

4. There must be ways to keep people safe. This includes stopping supporters who don’t respect what a person wants.

5. Everyone should use the principled approach. This will make sure no one is left out of supported decision-making.
6. When a person has trouble explaining what they want, their supporters need to try to understand them.

7. People should get support to take risks.

   But if it will hurt the person, someone else should make the decision for them.

   They should find a way to do what the person wants without them getting hurt.

8. Many people don’t have unpaid supporters.

   New programs and support should focus on this group of people first.

9. It’s important to work with people with cognitive disability and their supporters to set up how supported decision-making works.
Making the framework happen

There are 9 things we need to make supported decision-making happen.

1. Diversity

Diversity is what makes people different from each other.

People need different types of support to make decisions.
This means there isn’t one way to support everyone.

Supported decision-making programs should be different for different groups of people.

But everyone should use the same 9 principles.
We don’t know a lot about supported decision-making for some groups of people. We need to find out what type of programs will work best for these groups.

This includes:

- First Nations peoples
- people from different backgrounds.
2. Changing how we do things

Supported decision-making is part of everyday life.

To make sure everyone can get supported decision-making, we will need to change:

- policies
- laws.

Policies are:

- government plans for how to do things
- where rules come from.

This might include changing how NDIS nominees and guardians provide support.

These people act and make decisions for another person.

Service providers should also include supported decision-making as part of what they do.
3. Best practice

There is information about the best way to provide support for decision-making.

We call this best practice.

It’s important that supporters can find and share this information.

This will help them provide the best support they can.

We still need to find the best way to support people with cognitive disability when their disability really affects their day-to-day life.

We also need to find out how the law affects supporters.
4. Making sure everyone knows about supported decision-making

Everyone needs to know about supported decision-making. This will make sure people with disability get the support they need.

We need to have training about supported decision-making for:

- supporters
- service providers.

We should also have training for people with cognitive disability so they can:

- understand their right to supported decision-making
- learn more about making their own decisions.
5. Making sure supporters do the right thing

There needs to be a way of making sure supporters provide good support for decision-making.

Supporters can learn how to provide good support through:

- doing training
- sharing information with other supporters.

There should be a way for people to make a **complaint** about:

- supporters
- the support they get.

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

- has gone wrong
- isn’t working well.
6. The future

Sometimes people want to plan for a time when they:

- get older
- have trouble making decisions.

We call this forward planning.

The laws about forward planning need to change to include supported decision-making.

The laws should also help people to choose supporters that know them well.
7. Funding for supported decision-making

Funding is an important part of making sure supported decision-making happens.

Funding is money from the government to pay for supports and services.

This includes funding for:

- training supporters
- making sure everyone knows about supported decision-making.

Funding will be important for making sure everyone can get support to make decisions.

People could get funding so they can pay people to be their supporters.
8. Getting more supporters

Many people don’t have family or friends that can help them with supported decision-making.

Finding new friends and people to be supporters means a person with cognitive disability:

- will have better support for decision-making

- won’t have to rely on paid supporters.

But finding new friends and unpaid supporters is hard.

We need to find the best way of helping people with cognitive disability to find unpaid supporters.
9. Co-design

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

It’s important to work with people with cognitive disability and their supporters to set up supported decision-making programs.

It can be hard to do this well. This is because people who have trouble communicating can be left out.

We need more research about the best way of working with and including all people with cognitive disability.
Word list

This list explains what the bold words in this report mean.

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

Cognitive disability
A cognitive disability affects how people:
- think
- communicate
- understand
- focus on what they’re doing
- remember.

Complaint
When you make a complaint, you tell someone that something:
- has gone wrong
- isn’t working well.

Diversity
Diversity is what makes people different from each other.
Framework
A framework is a plan for how things should work.

Nominee or guardian
These people act and make decisions for another person.

Policies
Policies are:
- government plans for how to do things
- where rules come from.

Principles
Principles are important ideas we should always think about.
Rights

Rights are rules about how everyone should be treated fairly and equally.

Summary

A summary only includes the most important ideas.
Contact us

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We are available Monday to Friday.

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We are not available on public holidays.
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