



**NDIS Quality
and Safeguards
Commission**

Patterns of death for people using disability support services

A report about why some people with disability have died earlier than most Australians

Easy Read summary



How to use this report



The NDIS Quality and Safeguards Commission (NDIS Commission) wrote this Easy Read report.

It is a summary of a report by the Australian Institute of Health and Welfare (AIHW).

This means it only includes the most important ideas.



When you see the word 'we', it means the AIHW and the NDIS Commission.



We wrote this report in an easy to read way.

We use pictures to explain some ideas.

Not bold
Bold

We have written some words in **bold**.

This means the letters are thicker and darker.



We explain what these words mean.

There is a list of these words on page 29.



You can find the other report on the AIHW website at www.aihw.gov.au/reports/disability-services/mortality-patterns-of-people-using-disability-serv/contents/summary

In this report, we talk about some things that might upset some people.



If you read things that upset you, you should tell someone you trust.



In this report we also talk about **suicide**.

Suicide is when someone chooses to end their own life.

If you need to talk to someone, please contact:



Lifeline

13 11 14



Beyond Blue

1300 224 636



You can ask for help to read this report.

A friend, family member or support person may be able to help you.

What's in this report?

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What is this report about?



This report is about a study we did.

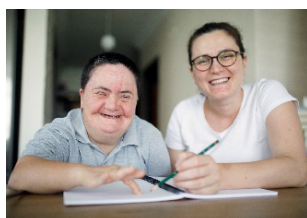


The study looked at patterns of death for people using disability support services.

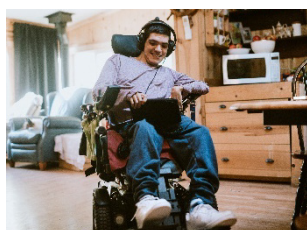


This means we looked at how and why some people who use **disability support services** have died.

Disability support services:



- help people with disability take part in daily life



- give people with disability homes and places to live



- look after people with disability so carers can have a break.

They also include services that support people with disability to:



- live in the community
- take part in the community
- build life skills.



This is the first report about why people who use disability support services in Australia have died.

We hope it helps reduce how often people who use disability support services:



- get sick
- get injured
- die.

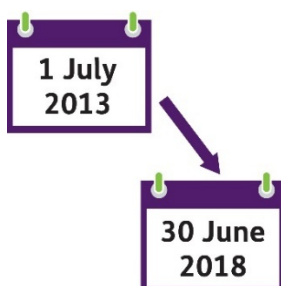
What did we look at?



We looked at 526,515 people with disability who used disability support services.



These people were all younger than 65.



We looked at what happened from:

- 1 July 2013
- to
- 30 June 2018.



We only included people who used disability support services paid for by the **National Disability Agreement (NDA)**.



The NDA was an agreement between governments around Australia.



The NDA was about how people with disability would use disability support services.



The **National Disability Insurance Scheme (NDIS)** looks after most disability support services now.



The NDIS helps people with disability get the supports and services they need.



We found out a lot about why people with disability who use disability support services have died.



This report talks about what we found out in 2 main areas:

- different types of disability
- different disability support services.



We talk about why people with different types of disability have died on page 14.



We talk about why people who use different disability support services have died on page 22.

What did we find out?



We found that people with disability in the study were almost 5 times more likely to die than the Australian population.



We also found that often people with disability died earlier than other people.



We don't have information about all people with disability.

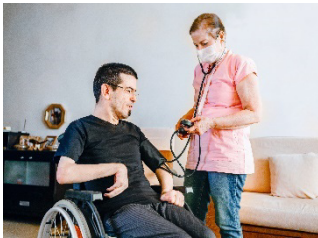


We only have information about people who used disability support services.



We hope to have information about more people in the future.

Many people who used disability support services died because of:



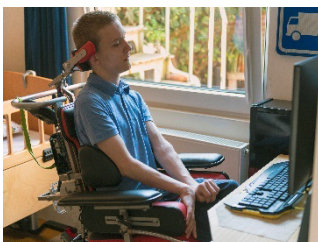
- **perinatal and congenital conditions** – disabilities that stopped their body growing in the right way



- **spinal muscular atrophy** – a disability that stopped their muscles from working in the right way



- heart disease



- **cerebral palsy** – a physical disability that affects how well you can move your body



- **epilepsy** – a health condition that affects how well your brain works. It can cause people to:
 - suddenly lose control of their body
 - pass out



- suicide



- accidental poisoning.



We also found that people with disability had higher rates of **potentially avoidable deaths**.



If something is avoidable, it means you can stop it from happening.

75↓



Potentially avoidable deaths include deaths for people aged under 75 years old.



These include deaths from illnesses which can be treated to lower the number of deaths.



It's important to look at potentially avoidable deaths to work out how well our health care system is working.

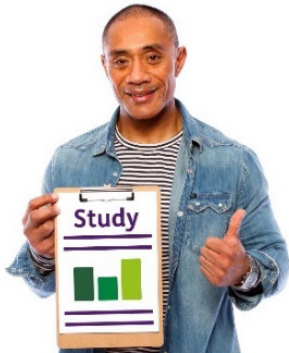
The main potentially avoidable causes of death for people in our study included:



- heart disease
- suicide.



These are also the main potentially avoidable causes of death for people without disability.



We will use the information from this study to work out some ways to help reduce potentially avoidable deaths.

The main cause of death for different types of disabilities



We looked at people with different types of disability.



We looked at people with **intellectual or learning disability**.



These disabilities make it hard for someone to:

- learn new things
- solve problems
- communicate
- do things on their own.



We looked at people with **physical disability**.



This disability affects how well someone can:

- move
- use their body.



We looked at people with **psychosocial disability**.



This disability affects someone's mental health.



It can affect the way you:

- think
- feel
- deal with other people.



We looked at people with speech or **sensory disability**.



A sensory disability affects someone's senses, such as their:

- sight
- hearing.

People with intellectual or learning disability



This group includes people with:

- intellectual disability
- learning disability
- Autism.

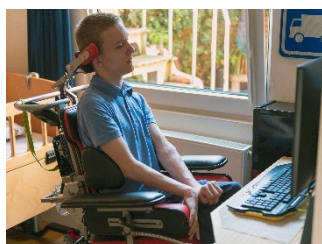


It also includes people with a **developmental delay.**

This is when a child hasn't grown the same way as other children their age.

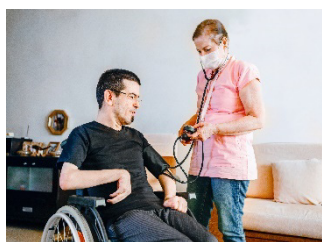


26% of people who died were people with intellectual or learning disability.



The main reason people aged 20–49 died was because of:

- cerebral palsy
- problems caused by cerebral palsy.



The main reason people aged 50–64 died was because of:

- perinatal and congenital conditions
- problems caused by perinatal and congenital conditions.

People with physical disability

This group includes people:



- with brain injuries
- who have problems with their:
 - muscles
 - joints
 - bones
- with a disability caused by damage to the body's **nervous system**.

Your nervous system controls your body and helps you do things like:



- walk
- talk
- swallow
- breathe.



49% of people who died were people with physical disability.



The main reason people aged 20–34 died was because of diseases that affect their **neuromuscular junction**.



The neuromuscular junction helps your body move its muscles.



These diseases can make your muscles feel:

- sore
- weak
- stiff.



These diseases can also make it hard to:

- breathe
- swallow.



The main reason people aged 35–64 died was because of spinal muscular atrophy.

People with psychosocial disability

This group includes people with:



- **depression** – a serious mental health problem that can make you feel sad
- **anxiety** – a serious mental health problem that can make you feel stressed and worried
- **post-traumatic stress disorder (PTSD).**



PTSD is a mental health problem you can have if you experience a **trauma**.

Trauma is something bad that happens to you that can make you feel:



- scared
- stressed
- worried.

It can include:



- the death of someone in your family
- a bad car accident
- your parents separating.



16% of people who died were people with psychosocial disability.



The main reason people aged 20–49 died was suicide.



The main reason people aged 50–64 died was heart disease.

People with speech or sensory disability



This group includes people who:

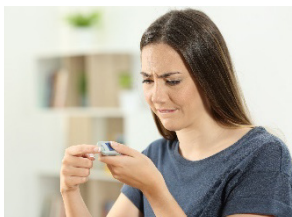
- are deaf
- are blind
- have trouble talking.



4% of people who died were people with a speech or sensory disability.



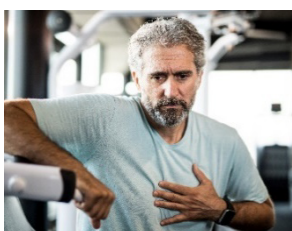
The main reason people aged 20–34 died was suicide.



The main reason people aged 35–49 died was **diabetes**.



Diabetes is a disease that causes high sugar levels in your body.



The main reason people aged 50–64 died was heart disease.

The main cause of death for different types of disability support services

We looked at the main cause of death for different disability support services, including:



- places where people with disability live



- support services that visit your home



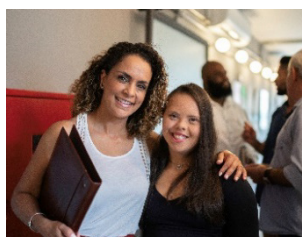
- services that look after people with disability so carers can have a break



- community support services



- services to take part in the community



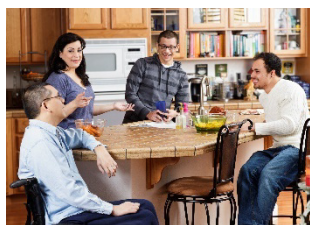
- employment services.

Places where people with disability live



Places where people with disability might live include:

- group homes
- accommodation with 24-hour care
- hostels.



We also call these residential accommodation services.



9% of people in the study used residential accommodation services.



18% of people who died were people who used services that provide homes for people with disability.



The main reasons people died were:

- perinatal and congenital conditions
- cerebral palsy
- epilepsy.

Support services that visit your home



These services include:

- support for your personal care
- support in your home
- a place to stay away from your home for a short time.



7%

7% of people in the study used other accommodation services, like support to live in your home.

15%



15% of people who died were people who used support services that visited their home.



The main reasons people died were because of:

- spinal muscular atrophy
- cerebral palsy
- heart disease.

Services that look after people with disability so carers can have a break



Respite services are services that look after people with disability so carers can have a break.

9%



9% of people in the study used respite services.



9%



9% of people who died used respite services.



The main reasons people died were because of:

- spinal muscular atrophy
- cerebral palsy
- perinatal and congenital conditions.

Community support services



Community support services support a person with disability to live in their own home.

43%



43% of people in the study used community support services.

62%



62% of people who died were people who used community support services.



The main reasons people died were because of:

- spinal muscular atrophy
- cerebral palsy
- perinatal and congenital conditions.

Services to take part in the community



Services to take part in the community support people with disability to join activities in their community.



15% of people in the study used services to take part in the community.



18% of people who died were people who used services to take part in the community.



The main reasons people died were because of:

- perinatal and congenital conditions
- cerebral palsy
- epilepsy.

Employment services



Employment services help people with disability find and keep a job.

50%



50% of people in the study used employment services.

22%



22% of people who died were people who used employment services.



The main reasons people died were because of:

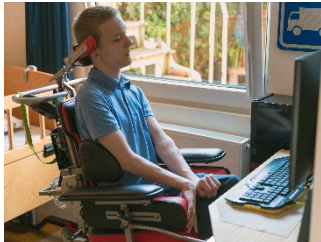
- suicide
- heart disease
- they were poisoned by accident.

Word list



Anxiety

A serious mental health problem that can make you feel stressed and worried.



Cerebral palsy

A physical disability that affects how well you can move your body.



Depression

A serious mental health problem that can make you feel sad.



Developmental delay

This is when a child hasn't grown the same way as other children their age.



Diabetes

A disease that causes high sugar levels in your body.

Disability support services

Services that:



- help people with disability take part in daily life
- give people with disability homes and places to live
- look after people with disability so carers can have a break.

Epilepsy

A health condition that affects how well your brain works. It can cause people to:



- suddenly lose control of their body
- pass out.

Employment services

Services that help people with disability find and keep a job.



Intellectual or learning disability

These disabilities make it hard for someone to:



- learn new things
- solve problems
- communicate
- do things on their own.



National Disability Agreement (NDA)

The NDA was an agreement between governments around Australia about how people with disability would use disability support services.



National Disability Insurance Scheme (NDIS)

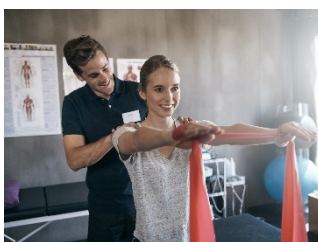
The NDIS helps people with disability get the supports and services they need.



Nervous system

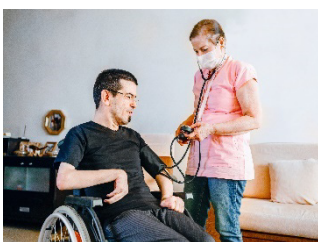
Your nervous system controls your body and helps you do things like:

- walk
- talk
- swallow
- breathe.



Neuromuscular junction

The neuromuscular junction helps your body move its muscles.



Perinatal and congenital conditions

Disabilities that stop your body growing in the right way.



Physical disability

A disability that affects how well someone can:

- move
- use their body.



Post-traumatic stress disorder (PTSD)

PTSD is a mental health problem you can have if you experience a trauma.

Potentially avoidable deaths

If something is avoidable, it means you can stop it from happening.



These are deaths for people aged under 75 years old.

They include deaths from illnesses which can be treated to lower the number of deaths.

Psychosocial disability

A disability that affects your mental health.

It can affect the way you:



- think
- feel
- deal with other people.



Respite

Services that look after people with disability so carers can have a break.



Sensory disability

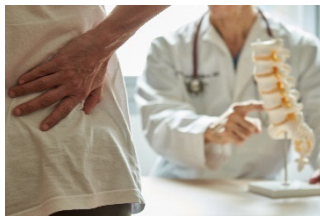
A disability that affects someone's senses, such as their:

- sight
- hearing.



Suicide

Suicide is when someone chooses to end their own life.



Spinal muscular atrophy

A disability that stops your muscles from working in the right way.



Trauma

Trauma is something bad that happens to you that can make you feel:

- scared
- stressed
- worried.

Contact us



NDIS Quality
and Safeguards
Commission

The NDIS Quality and Safeguards Commission wrote this Easy Read report.



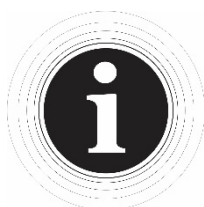
Australian Government
Australian Institute of
Health and Welfare

It is based on a report by the Australian Institute of Health and Welfare.



If you want more information about the report, you can email the Australian Institute of Health and Welfare.

info@aihw.gov.au



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