National Centre of Excellence in Intellectual Disability Health

Preventive Healthcare for People with Intellectual Disability



This paper is about preventive healthcare for people with intellectual disability in Australia.



Preventive healthcare means healthcare that helps stop illness before it becomes serious.

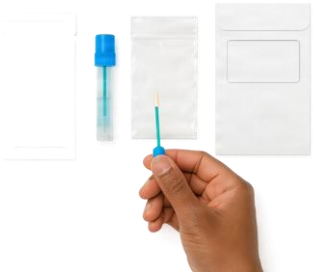


It includes things like

- Vaccinations



- Health checks



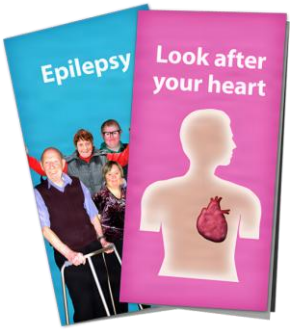
- Screening tests



- Support to eat well



- Be active



- Checking heart health



- Support to manage health risks early



People with Intellectual disability have the same right to good healthcare as everyone else.



This right is included in the united nations convention on the rights of people with disabilities.



This is sometimes called Article 25.



Article 25 says that people with disability should be able to get healthcare that is

- Accessible



- Respectful



- Of good quality

What is the problem



People with intellectual disability often have poorer health than people without intellectual disability.



They are more likely to have health problems that could have been stopped or treated earlier.



They may also die younger than people without intellectual disability.



This is not because people with intellectual disability do not care about their health.

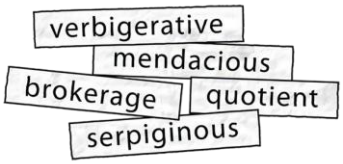


It is often because healthcare systems are not designed to meet their needs.



For example people may experience

- Health information that is hard to understand



- Doctors using hard words or speaking to quickly



- Short appointments that do not give enough time



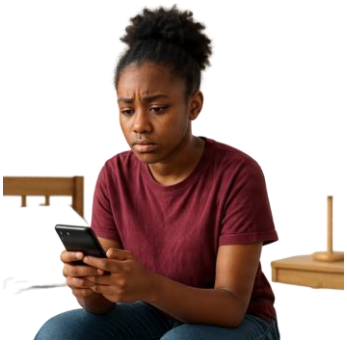
- Healthcare workers speaking only to support workers instead of directly to the person



- Difficulty booking appointments online



- Problems getting transport to appointments



- not getting reminders or follow up support



- services that do not work well together



- staff who have not had enough training about intellectual disability

What does this paper look at



This paper looked at Australian policies about preventive healthcare.



It focused on whether these policies help Australia meet its responsibilities under Article 25.



The paper looked closely at two areas of preventive healthcare.



1. vaccinations



2. preventing heart disease and stroke



The paper also included the views of co authors with intellectual disability.

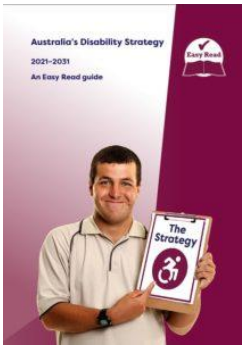


Their experiences were important because they showed what healthcare feels like in real life.

What did the paper find?



Australia has some good policies and programs.

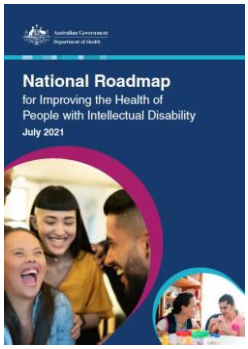


For example there is

- Australias Disability Strategy



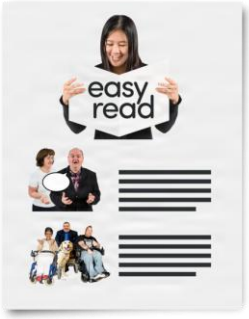
- The National Preventive Health Strategy



- The National Roadmap for Improving the Health of People with Intellectual Disability



- Annual health assessments for people with intellectual disability



- Easy Read health information



- Training resources for healthcare workers



These are important steps forward.



But the paper found that policies do not always lead to

- better experiences



- better health outcomes.



Many policies say that people with disability are important.



However they do not always explain exactly how services should make healthcare accessible and inclusive.



This means that people with intellectual disability can still miss out on preventive healthcare.

Vaccinations



Vaccinations help protect people from serious illnesses.



People with intellectual disability may be more likely to become very unwell from some infections.



They may still find it harder to get vaccinated.



During COVID-19 some people with disability had problems

- Getting clear information



- Booking appointments



- Accessing vaccination clinics



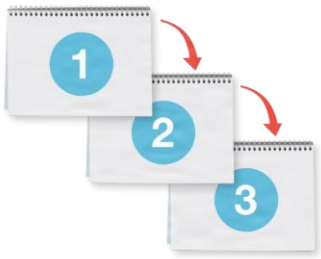
Some Easy Read information was delayed.



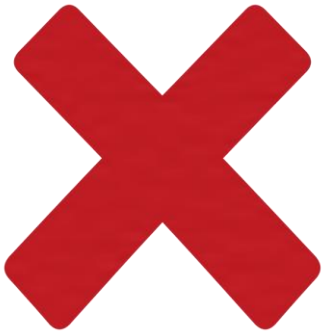
Some online information was not accessible.



Some people were not included in important decisions about the vaccination rollout.



The paper says that accessible information and disability inclusion should be planned from the beginning.



They should not be added later.

Heart health

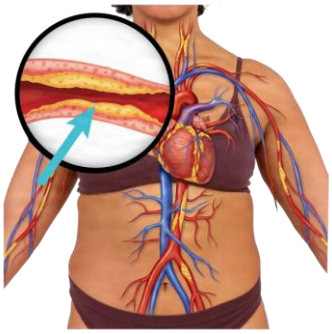


Heart disease and stroke can often be stopped.

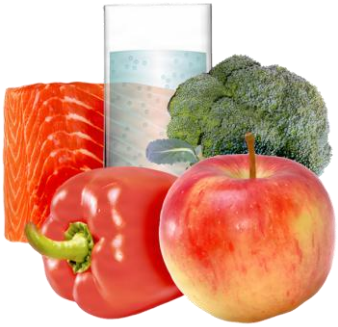


Preventing heart disease may include checking

- Blood pressure



- Cholesterol



- Diet



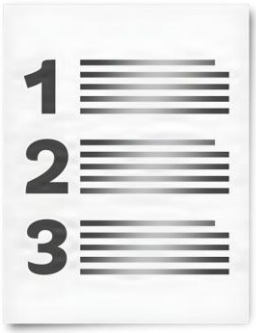
- Exercise



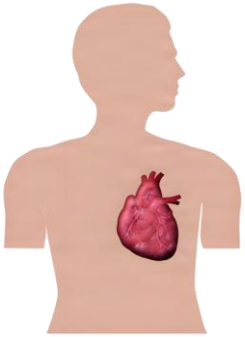
- Smoking



- Diabetes



- Other health risks



People with intellectual disability may have a higher risk of heart disease and stroke.



However they may not always receive regular heart health checks or support to manage health risks.



Some people may find it hard to join exercise or rehabilitation programs because of



- Cost



- Transport



- Lack of support worker time



- Programs that are not accessible



Healthcare services may also not make sure that people receive follow-up care after leaving hospital.



The paper says that preventing heart disease should not depend on a person who can organise everything for them such as.



- Family members



- Support workers



The healthcare system should take responsibility for helping people

- Attend appointments



- Understand information



- Receive follow up care

What did co-authors with intellectual disability say?

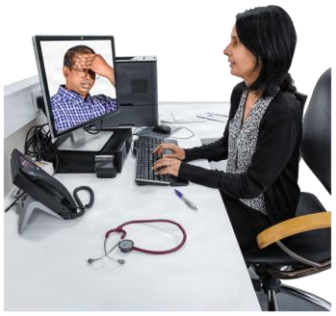


Co authors with intellectual disability said that healthcare can be difficult when doctors

- use hard words



- speak too quickly



- rush appointments



- do not explain things clearly



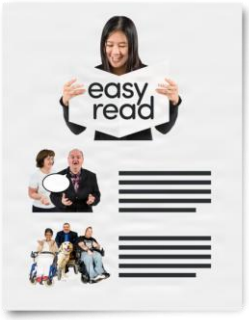
- talk only to support workers



- do not give people enough time to ask questions



They said that people should be spoken to directly and treated as the main person in their own healthcare appointment.

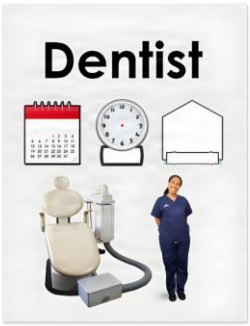


They also said that helpful changes could include

- Easy read information



- Videos and pictures



- Reminders about appointments



- Phone calls



- Text messages



- Calmer waiting rooms



- Quieter spaces in hospitals and clinics



- Health services organising follow up support



Better communication between

- Doctors



- Hospitals



- Disability services



- Support workers

What needs to change



The paper says that Australia needs stronger action.



People with intellectual disability should be included in preventive health programs by



- Planning



- Running



- Checking



They should not only be asked for feedback after decisions have already been made.



Health services should be expected to provide reasonable adjustments.



This means making changes so people can access healthcare fairly.



Examples include

- Longer appointments



- Accessible communication



- Supported decision making



- Sensory friendly spaces



- Appointment reminders



- Help with follow up



- Flexible ways to attend appointments



- Staff training about intellectual disability



Healthcare workers also need better training.



Training about intellectual disability should be part of

- University courses



- Professional registration



- Ongoing professional learning



Australia also needs better data.



Health systems should collect and report information about whether people with intellectual disability are receiving preventive healthcare.



This would help governments and services see where people are missing out and take action.

Key message



People with intellectual disability have the right to preventive healthcare that is



- Accessible



- Respectful



- Effective



Australia has made some progress.



There are still many barriers.



Better policies are not enough.



Healthcare systems must be designed with people with intellectual disability from the beginning.



People with intellectual disability should be partners in decisions about



- Healthcare policy



- Services



- Research



This will help make preventive healthcare works for everyone.

National Centre of Excellence in Intellectual Disability Health



Who wrote this Easy Read

Tahli Hind, Chinekwu Edom, Susan Adrian and Maryann Barrington.

Where these people work

3DN

UNSW Department of Developmental Disability Neuropsychiatry

Department of Developmental Disability Neuropsychiatry UNSW Sydney.

Also known as 3DN.

3DN is now a part o the National Centre of Excellence in Intellectual Disability Health.

National Centre of Excellence in Intellectual Disability Health



© Department of Developmental Disability Neuropsychiatry UNSW Sydney 23.10.26 v1

No changes can be made without asking the people who wrote this sheet.