



# **Leave No-one Behind**

## **Advocacy Platform**

**2019**



## What is this paper about?



**Down Syndrome Australia** wrote this paper. Down Syndrome Australia is the national organisation that speaks out for Australians with Down syndrome.

The paper is an **Advocacy Platform** that says that there are problems for Australians with Down syndrome and their families.

**Leave No-one Behind** means the problems need to be fixed so that people with Down syndrome aren't worse off than other people.



Down Syndrome Australia wrote the paper so that politicians understand these issues.



We want all the political parties to say what they will do to fix them so that people with Down syndrome aren't worse off than other people.

This will help people decide who to vote for in the next federal election.



We wrote this information in an easy to read way. We use pictures to explain some ideas. We explain words that are in **bold**.



You might like to get someone to help to read this paper. This could be your family, or a friend or support person.



## What are the main issues for Australians with Down syndrome?

People with Down syndrome are now living longer, healthier lives. More people with Down syndrome are now going to regular schools and getting jobs.

But people with Down syndrome still face problems getting their rights.



Here is a list of where there are problems for people with Down syndrome and their families.

- Prenatal screening
- NDIS
- Health
- Education
- Employment
- Migration
- Advocacy
- Housing



This paper has more information about each of these and says how to fix the problems.



## Prenatal Screening

There are a few different tests that can show if an unborn baby might have a disability. Some are blood tests and some are other kinds of tests such as ultrasounds.



But a number of people having these tests are having trouble getting the information they need.

Some doctors are giving out of date information.

Families are not hearing about the positive things about Down syndrome.



If people only get bad information about Down syndrome, they often choose not to have the baby.



Down Syndrome Australia says the government needs to change the system so that parents get the right information about the tests and good information about Down syndrome.



Down Syndrome Australia says there needs to be:

- Training for health professionals so they can give parents the best information and support.



- **Counselling** for parents about expecting a baby with Down syndrome, This is a professional person to talk with.



They should also get the chance to connect with other families through their Down syndrome organisation.



- **A public awareness campaign.** This is information, such as adverts, to make sure the community has true and positive information about Down syndrome.



## NDIS

The NDIS is a new way of helping people with disability get the services and support they need.

It is working well for lots of people, but not everyone.



People with Down syndrome and their families are having problems with some things about the NDIS.



This includes:

- Paying lots of money for specialist reports to show they should get an NDIS plan.
- NDIS planning staff not understanding about Down syndrome.
- Getting wrong information about the services they can get through the NDIS.
- Problems getting the services they need.



Down Syndrome Australia supports the **Every Australian Counts, Make it Work** campaign.

This is lots of people and organisations working together to tell government how to make the NDIS better.







Down Syndrome Australia says the government needs to make some changes so that the NDIS works well for people with Down syndrome.



The changes include making sure:

- People with Down syndrome can get NDIS plans without having to get lots of expensive reports to prove they need support.



- NDIS planners get better training about Down syndrome.



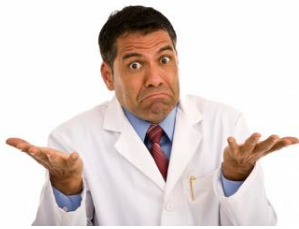
- People and their families get help to find the services they need to make their NDIS plan work.



## Health Inequalities

People with intellectual disability, such as Down syndrome, have more health problems than other people.

Most doctors and nurses do not get enough training about how to look after people with intellectual disability.



They may not know much about the health problems people with intellectual disability can have.



They may also not be good at communicating with people with intellectual disability.



This means that people often don't get the care they need, and their health problems get worse.

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Down Syndrome Australia says the government needs to make sure people with intellectual disability get good health care.



The government needs to:

- Set up programs so that doctors and other health services can give good care to people with intellectual disability.



- Make sure that student doctors and nurses in universities learn about good health care for people with intellectual disability.



- Have an **inquiry**. This is working out what the problems are so that people with intellectual disability get better health care in future.



## Education

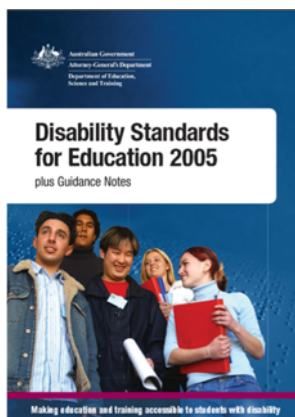
Australian children with disabilities have the right to go to **mainstream** schools. These are schools where children with and without disabilities learn in classrooms together. This is called **inclusion**.



People have done **research** to see what kind of schools are best. They looked carefully and found that all children do better when they go to mainstream schools.



But more than half of children with Down syndrome still go to schools and classrooms that are just for children with disabilities.



Down Syndrome Australia says that Australian and state governments need to make changes so that all children can have their right to inclusion.



Here are the changes:

Governments need to make sure:

- Laws are changed so that inclusion means the same across Australia.



- There is money and expert staff to help all schools include all children

- Teachers get training and support to make inclusion work. Down syndrome organisations should help with this.



- Schools help each child to learn the same things together, but in ways that work best for them.



- Anyone can easily make complaints about education.



- Parents can get good information and support to help their children be included in school.

## Employment



People with Down syndrome have the right to work and want to work, just like everyone else.

People have done research about people with intellectual disability and jobs.



They learned that people do better in their lives if they work in **open employment**. This is jobs in the community with people with and without disabilities.

But lots of people with Down syndrome still work in Australian Disability Enterprises, or **ADEs**, and don't get much pay. These are workplaces just for people with disabilities.

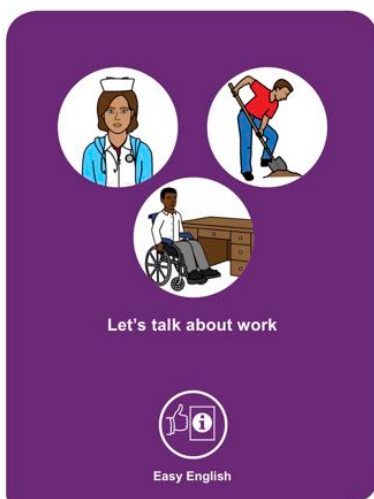


Down Syndrome Australia says this has to change, so that people with Down syndrome can work in open employment with fair pay.

The changes need to include:

- 'Open employment first'. This means that NDIS should give people money in their plans to help them find and keep jobs in the community.

NDIS should only give money to support people to work in ADEs when they have thought about open employment, education, training and volunteering first.







The government needs to make other changes including:

- Better support and chances for students with intellectual disability to move to open employment instead of ADEs.



- Making it easier for people with intellectual disability to use **Disability Employment Services, or DES.**

DES helps people with disability to get jobs, but the rules make it hard for people with intellectual disability to get support from a DES.



- More DES providers that specialise in helping people with intellectual disability to find and keep a job.

These specialist DES should get more money from the government to give people more support over a longer time.



- Better **further education** for people with intellectual disability. This is more education for people who have left school, such as TAFEs and other courses.

## Migration



Migration is when people leave their home country and go to spend the rest of their lives in another country.

Lots of people migrate to Australia. They have to follow the government's rules if they want to come and live here.



One of these rules is that people who want to migrate should have good health. The government says this is because it will cost Australia lots of money to look after people who are unhealthy.

The government also uses this rule to say it will cost too much money to support people with disability.



So the government won't let people with disability migrate to Australia.



Disability Discrimination Act 1992

Down Syndrome Australia says this is **discrimination**. This means that people with disability are treated differently from other people, and this is not fair.

But the law about disability discrimination doesn't cover migration.



Down Syndrome Australia says that the Australian migration system should see that people with disabilities bring good things to the community





Australia said it would follow the **UN Convention on the Rights of Persons with Disability (UNCRPD)**. This is international rules about disability. But they decided not to follow the UNCRPD rules about migration.



In 2012, when lots of Australians said the rules were unfair, the government said it would make some changes. But they didn't.

Down Syndrome Australia says the government needs to do some things so that Australia does not discriminate against people with disabilities.

These are:



Disability Discrimination Act 1992

- Make the changes the government said they would do in 2012.
- Make changes to the Disability Discrimination law and the migration rules so that people with disabilities have the same migration rights as other people.



- Follow all the UNCRPD rules, including Migration.

Canada 

- Look at what other countries, such as Canada, are doing to make their migration rules fair to people with disabilities.



## Sustainable funding for disability specific peak organisations



Down Syndrome Australia is a **disability specific peak organisation**. This means we speak out for Australians with Down syndrome and their families.

But the government only gives a small amount of money to Down Syndrome Australia and other organisations that speak out for people with other disabilities.



The funding isn't enough for the organisations to be **sustainable**. This means there isn't enough money to do all our important work.



We have to try other ways to find the money we need.

This is usually **project** money. This means it can only be used for a certain thing and only lasts for a short time.



It takes a lot of time to find this extra money and takes us away from the most important work we do.



This work is:

- Speaking out for people with Down syndrome and their families, and
- Giving expert advice to government on things that are important to people with Down syndrome.



Down Syndrome Australia says that government should give disability specific peak organisations enough money to do all this work.

There are 10 of these organisations that make up the **Disability Australia Consortium**.

This is a group of organisations that are separate but sometimes work together.



The government should give each of the 10 organisations \$220,000 each year to do their important work.



## Affordable Housing

People with disabilities need housing they can afford.



It needs to be close to public transport so that people can have a good life that includes:

- Going to work
- Health services they can get to easily
- Getting together with family and friends
- Doing things they want in their community



People with disabilities often don't have much income. Lots of people only have their Disability Support Pension.

But in Australia there isn't enough housing they can afford or is close to transport.



So people with disabilities often can't get the housing they need to help them have a good life.



The UNCRPD says that having affordable and safe housing is a right for people with disability.

People should not have to live in places they don't want to just because there is no housing that is right for them.





Down Syndrome Australia says that the government needs to make some changes so that people with disabilities can get the housing they need and can afford.

The changes include that Government:



- Makes sure people get enough money in their Disability Support Pension so they can afford to pay for housing.



- Looks at the Rent Assistance allowance to make sure:
  - People can get it, and
  - It keeps up with the cost of living.



- Makes sure there is always plenty of affordable housing that suits everyone, including people with disabilities.