

A Report for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability by the Victorian Disability Services Commissioner - Plain English

My name is Arthur Rogers. This is my report that I gave to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

This report is written in Plain English. It is written for everyday people to understand.

It is a summary of my long report. The long report is called Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: June 2020.

We acknowledge the Traditional Owners of country throughout Australia and recognise their continuing connection to land, waters, and culture. We pay our respects to their Elders past, present and emerging.

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Background to the Report

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Royal Commission) is a group of people who have got together about one issue. They want to learn more about problems for people with disability. They want to learn how to prevent those problems in the future.

The Royal Commission gets information from many different places. Many people are talking at the Royal Commission. I talked to the Royal Commission. The Royal Commission also gets reports from people with disability and organisations.

This is my report as the Victorian Disability Services Commissioner. The Disability Services Commissioner is sometimes called the DSC. In this report, I have written down what I am concerned about for people with disability. I have used information from the work that we do at the DSC. I have used information from research and other reports done about people with disability in Australia. I have thought a lot about this information.

I have thought about the violence, abuse, neglect, and exploitation of people with disability in disability services. It is wrong. It should not happen. We need to prevent these very bad things from happening. We need to respond better when very bad things happen.

I think there are many things that need to change. There are four big ideas that are in my report:

1. There needs to be changes in how everyone thinks about people with disability.
2. Disability service providers need to be better at providing different ways of supporting people and have trained staff who can provide safe and great homes and services.
3. There needs to be somebody responsible for watching the disability workforce to make sure violence, abuse, neglect, and exploitation does not happen. They need to listen and respond to complaints.
4. All of the Australian community need to work together so people with disability have housing, health care, education, employment, and justice.

The things that need to change are called my recommendations for the Royal Commission.

A lot of my work has been done in Victoria, Australia. The Royal Commission is looking at people across Australia. Some of my recommendations are for Victoria and some are for Australia.

Each section of this report will include my concerns and my recommendations for what I think needs to happen to make things better.

There are six sections in this report:

1. Ways of thinking
2. Ways to prevent and protect people with disability from very bad things
3. Ways to respond when very bad things happen
4. Making Australia a better place for people with disability to live
5. Thinking about different groups of people with disability
6. Ways to support people, families, friends, and the disability workforce.

Important Terms

In this report I will talk about **people with disability**. A lot of my work has been with people with intellectual disability. Some of the work has been with people with other disabilities like physical or sensory disabilities. Some of my work has been with people who have disabilities from their birth, and some has been with people who acquired a disability as adults. Some people have a combination of disabilities.

This report is about violence, abuse, neglect, and exploitation of people with disability. The Royal Commission explains what all of these words mean on their website: <https://rcdisability.govcms.gov.au/about-royal-commission/key-terms>. To make this report easier to read, I will call these things **very bad things** which have happened to people with disability.

In this report there are some groups that we will talk about. These groups include:

- The National Disability Insurance Agency (NDIA)
- The National Disability Insurance Scheme (NDIS)
- The NDIS Quality and Safeguards Commission (NDIS Commission)
- Disability service providers who may provide residential (group home) services, day services, or respite services.

About the Disability Services Commissioner

The Disability Services Commissioner works with people with disability to fix complaints about disability service providers in Victoria.

We hear lots of complaints about services. We have learnt about bad things happening to people with disability.

Very bad things such as violence, abuse, and exploitation against people with disability is wrong. It should not happen.

We have worked with people with disability and their disability service providers to make things better. Some problems are fixed by people talking together. Some problems need investigations and we need to learn more about the problem. Sometimes we need to tell services what they need to do to make things better.

We also read reports of when people have been hurt in their disability services. We learn about people who have died in disability services.

We help disability service providers in Victoria to do a better job for people with disability.

The way the Disability Services Commissioner works is changing. People who use the NDIS now talk to the NDIS Commission if they have a complaint. People who do not get NDIS services can still make their complaints to us.

1. Ways of thinking

Separating people with disability from everyone else

In the past many people with disability were locked away in institutions. They were not allowed to go to regular schools. They were treated like people who needed to be fixed. They were separated from community. This is called segregation.

Now, people with disability are part of the community. They can live in regular houses and go to regular schools.

But some services are stuck in the past. In some group homes, people are still treated like they live in an institution. In some group homes, most of the decisions are made by the manager and disability support workers.

Keeping people with disability apart from the rest of the community is called segregation. We think segregation is bad. We know that more very bad things happen in segregated places than in services that are not segregated.

Recommendation 1:

Group homes and other disability services that are not good enough should be improved or closed if they cannot follow the Convention on the Rights of Persons with Disabilities and follow Australian laws.

Human rights

Everybody has human rights. Over history, the rights of people with disability have been ignored too much. A special set of rights was written for people with disability called the *Convention on the Rights of Persons with Disabilities*. It says that people with disability have the same rights as everyone else. It says that people with disability can choose how to live their life.

The Australian Government said it agreed with the Convention. But the government does not have laws to make sure the Convention is followed.

Victoria has the *Charter of Human Rights and Responsibilities Act 2006 (Vic)*. But there is some confusion about who should follow the Charter. Some disability service providers say that they do not need to follow the Charter. Other service providers say they will follow the Charter, but this does not always happen.

Recommendation 2:

The Convention on the Rights of Persons with Disabilities needs to be written into Australian laws.

Recommendation 3:

The Victorian Government needs to be clear who must follow the Charter of Human Rights and Responsibilities.

A government plan about including people with disability

Too many people with disability are treated unfairly. Many people do not have enough money. Many people with disability cannot get jobs, even when they can do the work just like anyone else. Many people do not get a proper education.

The Australian Government wrote a plan called the National Disability Strategy 2010-2020 to make sure people with disability were not treated unfairly. Sometimes services followed the plan and sometimes they did not. Many people with disability were still not included in the community.

The Australian Government is writing a new plan. We think this plan is important. We think that there needs to be people in the government who are responsible for doing the new plan. There should be an Office of Disability that works with the Prime Minister and the government. They must listen to people with disability. People with disability know the problems they face and have good ideas about how to make things better.

Recommendation 4:

The Australian Government needs to finish the new National Disability Strategy and there needs to be someone high up in the government to make sure the strategy is made to happen.

Recommendation 5:

The new National Disability Strategy needs to be very clear for all Australians.

It needs to say:

- what should happen
- who will do things
- who will check if things have been done.

Recommendation 6:

People with disability and people who represent them must be involved in all steps of creating the new National Disability Strategy and checking that things have been done.

2. Ways to prevent and protect people with disability from very bad things

Person-centred active support

Person-centred practice is a way of working with people with disability that focuses on each person. When people work in a person-centred way, they look at what each person is good at doing. They look at what each person is interested in doing.

A person with disability can have a person-centred plan. A person-centred plan is a written report that says what support somebody needs to do the things that are important to them. A person-centred plan should be written by the person with disability, with the help they need. The person's family can help. The person's friends can help. They can all have a say about what should be in the plan.

Unfortunately, we see lots of bad person-centred plans. People have been left out of their plans. The goals are not clear. The plan does not say who will do things or when things will be done.

Sometimes people have a good plan, but nobody is following the plan.

Another way of working is active support. Active support is all about how to support somebody to do the things they want to do or need to do. It helps people to do things in their own home and to do things in the community.

Disability support can be good when person-centred practice and active support is used.

Recommendation 7:

Disability support workers and service managers should be trained to do person-centred practices and active support. The NDIS Commission should say when services must train their staff, and there needs to be enough NDIS funding for this to happen.

Understanding how people communicate and getting the help that they need to communicate best

Being able to communicate is very important. People with disability use lots of different ways to communicate. Some people use speech. Some people use sign language. Some people use their body and face to communicate. Communication is important for saying if you are sick or unhappy. Communication is important for saying if very bad things are happening.

Some people with disability should see a speech pathologist every year. A speech pathologist can write down how someone communicates. They can tell disability support workers what a person understands and how the person expresses themselves. A speech pathologist can say how to improve someone's communication so they can communicate with more people, more clearly.

Too many people living in group homes have not seen a speech pathologist.

Recommendation 8:

Some people with disability should see a speech pathologist every year. Disability support workers need to know more about communication. The NDIS Commission should say when services must train their staff, and there needs to be enough NDIS funding for this to happen.

Recommendation 9:

All governments in Australia need to write their information in ways that different people can understand. They need to write information in: plain English, captioning, Auslan, and Braille.

Supporting people who might use challenging behaviours

Some people with disability use challenging behaviours or behaviours of concern. Behaviours of concern happen when a person deliberately hurts themselves, hurts other people, or damages furniture or other things.

There are many ways to help someone so that they do not use behaviours of concern. People can be taught to express themselves in different ways. Places and people can be changed so someone does not use behaviours of concern anymore.

Sometimes, when things do not work to change the person's behaviours, restrictive practices are used. Restrictive practices include giving the person medication to change their behaviour, blocking or forcing a person's body so they can't move freely, using belts or body suits to stop someone from touching their body, or locking a person in a room by themselves.

Disability support providers must ask for special permission to use any restrictive practices. They must write a plan that says exactly what they will do.

We have seen too many disability support providers use restraints without permission. This is against the law. We have seen and read about services doing things that are unfair and dangerous to people who use behaviours of concern.

Positive behaviour support is one way of working with people who might use behaviours of concern. Positive behaviour support involves understanding the person. It involves understand the person's behaviours. It involves planning to help the person better, so they do not need to use those behaviours anymore. Positive behaviour support involves thinking about how to NOT use restrictive practices or to use as little restrictive practices as possible so that the person can live a good life.

Rules are being written for all Australians called the NDIS Restrictive Practices and Support Rules. This is important. Disability support

providers need to learn a lot more about positive behaviour support so that very bad things do not keep happening.

Recommendation 10:

Disability support workers need to know more about positive behaviour support. They need to know about restrictive practices. They need to know how to use restrictive practices less. The NDIS Commission should say when services must train their staff, and there needs to be enough NDIS funding for this to happen.

Support to make decisions

Some people with disability are very good at making their own decisions. They can make decisions about all the big and little things in their lives. People with disability have the right to make choices every day. They can choose what food to eat or clothes to wear, where to go and who they see, and when to go to bed.

Some people with disability need support to make decisions. They need clear information about their choices. They need people who know them well to help them. Families and friends can support the person to make decisions.

People with disability do not need someone to take away the decision from them; but they need help to have their say. This is sometimes called supported decision-making.

Everyone needs to learn about supported decision-making.

Some families and disability support workers are afraid to let the person with disability make decisions. They might need help to let the person make decisions.

Recommendation 11:

There needs to be a supported decision-making plan across Australia.

Recommendation 12:

Disability support workers need to know more about supported decision-making. The NDIS Commission should say when services must train their staff, and there needs to be enough NDIS funding for this to happen.

End of life care

One of the big decisions of life is how we want to die. We can have a say in the types of medical approaches that we want, where we want to die, and what we want to happen when we die.

Too many people with disability are not involved in making decisions about the end of their lives. Many disability service providers do not know how to help people with disability make decisions about the end of their life.

We learnt that sometimes families are expected to make the decisions, but this is not good if the family have not stayed connected with the person with disability. It is not good if doctors make all the decisions if they do not know the person. Some doctors seem to presume that a person's life is not worth living when they have a disability: this is not right.

The best decisions for end of life are made by the person with people they know well. They can plan. They can be told clearly what is happening. Some people with disability may need support to learn about what is happening around death.

Recommendation 8:

Disability support workers need to know more about how to support people to learn about death and dying and to make choices around the end of their life. The NDIS Commission should say when services must train their staff, and there needs to be enough NDIS funding for this to happen.

Teaching people about their health and preventing health problems

People with disability have higher chances of getting health problems. Many people with disability die younger than people without disability.

Many people with disability could live longer. There are many things that can help people live longer. There are health checks that can find small health problems before they become big problems. There are needles that can stop people from getting some illnesses. There are plans for healthy eating and exercise.

Too many people with disability miss health checks. Too many people do not go to the dentist. Too many doctors miss seeing health problems that they should see and do something about.

We have heard about many people with disability who have died. We have heard about people who should not have died. Too many people have choked on firm food, even when their support workers have been told to give them soft food. Too many people have died when they were getting sick because they did not see a doctor quickly.

Recommendation 14:

Disability support workers need to know more about the health of people with disability. They need to know about the risks of choking, chest infections, epilepsy, and constipation. The NDIS Commission should say when services must train their staff, and there needs to be enough NDIS funding for this to happen.

3. Ways to respond when very bad things happen

Complaints

Sometimes things are not good enough in disability services. Sometimes people with disability need to make a complaint.

It can be hard for people to make a complaint. Here are some reasons why it can be hard to make a complaint:

- People are afraid they will get in trouble
- People are afraid that the service will be taken away
- People do not know what their rights are
- People have complained before and it did not go well for them
- People do not have the support to communicate
- People do not know that things can be better.

Disability service providers need to have ways to help people make complaints.

We have done a lot of work to help people know about making complaints. We have taught a lot of people that 'It's OK to complain'. We have taught people that making complaints can make disability services better for everyone.

The NDIS Commission is also teaching people about complaints. We like that the NDIS Commission makes sure that disability service providers have ways to deal with complaints.

The NDIS Commission has important ways to deal with complaints about registered disability services. Registered means a service has said that they will follow the rules to make a service safe and good. Some services are not registered. They do not have to follow all the rules that registered services must. This can be a problem if very bad things happen in the service.

The NDIS Commission have important rules for all disability support workers. The Victorian Disability Worker Commission have rules not just

for NDIS support workers but all disability support workers. The rules can stop very bad disability support workers from working in Victoria.

Recommendation 15:

There needs to be a team of people who can work with complaints and let everyone know that it is okay to complain. The team can also teach disability support providers that complaints can make things better.

Recommendation 16:

People need to know more about what the NDIS Quality and Safeguards Framework can do about complaints and keeping people with disability safe.

What to do when very bad things happen

The Disability Services Commissioner can do something when serious incidents happen in disability services.

Sometimes we hear about things when we get incident reports from disability service providers. Disability service providers need to write incident reports when very bad things happen. They need to decide how serious the incident is. We get the very serious reports.

Sometimes disability service providers decide that an incident was not very serious. We do not hear about what happened. This can be a big problem. We cannot investigate when we do not know about the very bad thing that happened. There needs to be a better way for services to know when an incident is very bad for people with disability.

Here is an example. One person got hit in the face by somebody they lived with. The support workers decided that it was not very serious. We think this is very serious. We think we should have been told what happened.

Recommendation 17:

The NDIS Incident Management Rules must be clear about very serious incidents. Disability service providers must let the NDIS Commission know when very serious incidents happen.

Investigations and finding out what happened when somebody dies

The Disability Services Commissioner can do an investigation when we hear about very serious incidents. We can go into disability services and look at what is happening.

We can work with a service to make it better. We try to teach services to be better, instead of punishing services. This has made many disability services better. They have fixed the problems and made the service safer.

The NDIS Commission can investigate complaints. We know that doing good investigations takes a lot of time and a lot of money. The NDIS Commission needs to have the time and money to investigate problems properly.

The NDIS Commission says that disability service providers must let them know when someone dies.

In Victoria, we find out when people with disability die in disability services when the service provider lets the Department of Health and Human Services (DHHS) know. We are worried that some disability service providers do not know when they need to let DHHS know about a person dying. We are also worried that they do not know when they need to tell the State Coroner.

Sometimes people die because they are old. Sometimes people die before they should have. This can be called a preventable or unexpected death. When we are told, we decide if we need to investigate. We tell all disability service providers about what they can do to prevent people from dying early or accidentally.

We think that investigations of preventable deaths need to happen across all of Australia.

Recommendation 18:

There needs to be a way of knowing about and investigating deaths of people with disability. This needs to be the same across all of Australia.

Recommendation 19:

There needs to be clear rules about when to let the NDIS Commission and the State Coroner know about the death of a person with disability.

Community Visitors: People who visit group homes to see what is happening

In Victoria, there are a group of people called Community Visitors. Community Visitors are part of the Office of the Public Advocate.

Community Visitors have a special job. They visit group homes to see what is happening in the home. They talk to the people who live in the home. They are allowed to look at the reports written about the people. They can say if something does not seem right.

The Community Visitors can share some information with the NDIS Commission if they are worried about a person with disability.

The Office of the Public Advocate would like Community Visitors to also see people with disability in other places that they live, like boarding houses.

We think that Community Visitors are very important for making sure that people are safe and able to live good lives.

Recommendation 20:

There needs to be Community Visitors across Australia. There needs to be clear rules about how they work with the NDIS Commission.

Independent advocacy: Someone to help people with disability to say when things are not right

Some people with disability are very good at speaking up for themselves. They can make complaints for themselves. Some people can be taught to speak up for themselves. The NDIA have been helping people to learn how to speak up for themselves.

Some people need help from another person. Some people have friends or family who can help them speak up. The NDIA have been helping friends and family learn how to speak up for people with disability.

Some people do not have someone in their life who can speak up for them. An independent advocate is somebody from a different service who can stand beside the person with a disability and support them to have their say. Sometimes independent advocates can help a person and their family.

We are worried about independent advocacy. The work of advocates is becoming more complicated. We know that more people need more advocacy. We are seeing people who must wait a long time to get the advocacy services that they need.

Some advocates help individual people. Some advocates work for groups of people to make big changes. This is sometimes called systemic advocacy. For example, there is work that needs to be done for First Nations people with disability, and woman and girls with disability by systemic advocates.

Recommendation 21:

There needs to be more money for services that provide advocacy. There needs to be more advocates who can work with more people.

4. Making Australia a better place for people with disability to live

Somewhere to live

Some people with disability live with their family. Many people with disability live in group homes with other people with disability.

Lots of the people who live in group homes do not have a choice about who they live with. Some people live in houses that are not safe for them. Sometimes people have been hurt by the people they live with. We heard about one woman who was hurt lots of times by someone she lived with, but she was not able to leave that house.

It can be complicated to move to another group home. There are not enough places available to live and get support.

The NDIS are trying to give people more choice about where they live. They are trying to give people more choice about who provides disability services. But in Victoria, this is still complicated. If a person wants to change who does the support in their group home, they must convince everyone else in the house to change who provides the services.

We think that group homes could be built better. Group homes could be built that have more private places for each person. Group homes could be better if people could choose who they live with.

People should be able to choose other types of houses. They should be able to choose to live alone or choose to live with another person.

People should be able to get different sorts of supports like technology supports or changes to their house so they can live safely.

We know that buying a house is expensive. We know that renting can be expensive too. Too many people with disability end up homeless because things are expensive, buildings are not accessible, or landlords might not want to have a person with a disability in their building. There are not enough choices and the system is not always fair.

Some people with disability end up living in aged care settings, because they cannot get the support they need. Some people end up in boarding houses. Some people end up in prison because they have done crimes.

Recommendation 22:

There must be more choices for places where people with disability can live. There must be choice to live alone or with other people.

Recommendation 23:

There must be more accessible houses for people with disability to rent.

Recommendation 24:

People with disability may need support to understand their right to live where they want in the community. They may need paid supports that help them live the life they want.

Health

Some people with disability are healthy. But people with disability may not be healthy. Some people have lots of health problems. Many people do not get the healthcare services that they need. Many people have health problems that could be fixed but are not fixed.

Sometimes people need regular health care services like a regular doctor or dentist. Some people have great doctors. They have a doctor that spends time with them and does all their health checks. We know that sometimes doctors do not get paid enough for these long appointments. This can put doctors off doing long, detailed appointments.

Some people need specialists. Specialists can be expensive. Some people do not see the specialists that they need. They do not get the health services that they need.

Some people take many different medicines. Some of the medicines can help the person. Some people take too many medicines. The medicines can mix and have bad effects on the person's health. Doctors and disability support workers need to know about the effects that medicines have on people.

Another health risk for people with disability can be when they go to hospital. Sometimes health staff like nurses and doctors do not work well together with disability support workers. Lots of communication problems happen. Sometimes support workers do not give health staff the information they need. Sometimes health staff do not listen to disability support workers.

Sometimes people are not given enough support in hospital. One person was in hospital for 10 days and nobody from outside of the hospital visited them. They felt really lonely. A hospital can be a very frightening place for a person with disability.

Mistakes can happen when people leave hospital. People can miss out on the after-hospital health services that they need. Sometimes health staff think that disability support workers are nurses. They think that disability support workers will do health work that they cannot do.

Recommendation 25:

Medicare is the service across Australia that pays for many health services. Medicare needs to pay the full amount needed for doctors to care for people with disability.

Recommendation 26:

Health care professionals need to understand more about disability. They need to understand the rights of people with disability. People with disability and organisations that represent them, can be involved in teaching health care professionals.

Recommendation 27:

There needs to be more money and services for helping health and disability service providers to work together. There needs to be a group of disability health specialists across Australia to support people with complex health problems.

Dealing with police and courts

Sometimes people with disability need to talk to police. Some people have crimes done to them. Sometimes people feel that they do not get treated fairly by the police. We know people who have told the police about a crime, but the police did not seem to follow up. The police did not talk to the person again to tell them what had been done.

Sometimes police have decided not to do anything when a person with disability talked to them. Sometimes police think that the person is not telling the truth or would not be able to make legal decisions. Sometimes the police do not listen to the person, they decide to just talk to the person's family. This is not fair.

There is a service for people with disability called the Independent Third Person. This is someone who sits with a person with disability to make sure they understand what the police say and make sure the police understand the person. Unfortunately, an Independent Third Person is not always called or available when they are needed.

Police need to be trained to work with people with disability. They need to know how they can change the way they work so the person with a disability can report, talk about, and have justice for crimes.

Things are getting better. In Victoria, there are police disability liaison officers who support people with disability. We want to see more of these, so police know what to do when very bad things have happened to people with disability.

Recommendation 28:

There needs to be more disability liaison officers. Police need to understand disability better. They need to understand how to work with people with disability in a way that is fair.

Education: school

It is important that people with disability should be supported to go to mainstream schools like all other children. Going to mainstream schools will give them better education. Going to mainstream schools will help them get jobs. People with disability must be able to go to childcare services, kindergartens, schools, universities, TAFEs, and all the other services that people can use.

Education is an important way to try to protect people from very bad things happening. Unfortunately, some people with disability who choose to go to mainstream schools have been stopped from going there. Too many people are sent to special schools and are kept away from other children.

We know that there are lots of things that are blocking people with disability from their education:

- Not enough money to support the person
- Not enough specialist supports
- The teachers do not know enough about disability
- The teachers do not have enough time to plan good education
- People who discriminate and say they do not want people with disability in the school.

Recommendation 29:

A plan for all of Australia is needed so that children with disability can go to mainstream schools like other children.

Having a job

Too many people with disability do not have a job. There are lots of things that stop people with disability having a job, like:

- Not having a good education
- Not learning about how to get a job, and missing out on work experience or a job coach
- Other people having low expectations and thinking that people with disability cannot work
- Not getting fair help in a job to do what you need to do to succeed.

Some people get stuck in workplaces that are just for people with disability. These places do not always pay a fair amount for the work that the person does. Some people get stuck in day services. Some people do not get the help they need to get jobs like everyone else.

When people have no job or have a job that pays poorly, they can be at risk of living in poverty. Living in poverty causes so many problems. People get stuck in poverty.

Recommendation 30:

There needs to be more support for getting people with disability out of day services and sheltered employment, and into regular workplaces. People need fair pay for doing the same work as other people.

Everybody needs to understand about disability

Years ago, many people with disability lived shut away in institutions. Now people live in the community, but some people feel like they are still shut away. Some people feel like they are not respected by other people in Australia.

Some people with disability feel like they still do not have choices like everyone else in Australia. They feel like they are shut out from public transport. They feel like they are shut out from fun activities and education.

Some people are shut out because nobody thinks and plans for the person to join in regular things.

People with disability can do regular things. They can get jobs. They can join a library. They can go to the gym.

Some people in the community are frightened of people with disability. Some are nervous and do not know what to do. Some people in the community avoid people with disability.

The best way to get over fear or nervousness is to have good experiences with people with disability. When people have good experiences, they can see how people with disability belong in Australia just like everyone else.

People with disability can be the best teachers of the community. They can challenge stereotypes and bad attitudes. People with disability can teach on TV, in training courses, and every time they go out.

People with disability can show how successful they can be. There has been some great examples of talent and skills at the VALID Having a Say conference and during the 'Change your reactions' campaign about people with autism.

Recommendation 31:

There needs to be positive education across Australia about disability. People with disability and the organisations that represent them need to be involved. Money is needed for people with disability to lead conferences and campaigns.

5. Thinking about different groups of people with disability

Different groups of people with disabilities

There are so many different types of people in Australia. There are people from different cultures.

There are First Nations people and people born in different countries. There are male and female, and people with no gender or describe their gender differently. There are people of different ages, and people from different religions.

Different people have different needs. Different people with disability have different needs. It is important that we listen to different needs.

When we work with people, we try to learn about their different needs. When we write reports about people with disability, we try to understand the different groups of people.

Sometimes we do not have enough information about people with disability. This can be a problem, because we might be missing important information for a group of people.

The NDIS might be able to find out more about different groups of people with disability across Australia. They will be able to use the information to make decisions that will help different groups.

The NDIS could give some of the information (not personal information) to researchers and policy makers so they can work towards better services for people with disability.

Recommendation 32:

Across Australia, good information needs to be collected about different groups of people.

Recommendation 33:

The public need to know about very bad things happening in services that are paid for by NDIS. The public, researchers, and policy makers need to know about the number of people, so that they can focus on improving services.

First Nations people with disability

There are many First Nations people with disability in Australia. More very bad things can happen to First Nations people with disability because of health, discrimination, and other disadvantages. Many people have low education, low numbers of jobs, and poor health.

We have not seen many First Nations people in our work in Victoria. We think that many First Nations people do not want the typical services like group homes or day services. They want something different. They want services that help their whole family and community.

We need to think about the sorts of services that First Nations people and their families want. We need to talk with First Nations people about better services for them.

We need money to support First Nations people to become disability support workers and managers. We need First Nations people who can make their own disability services.

Disability service providers need to learn how to provide services that respect and fit the needs of First Nations people with disability.

The First Peoples Disability Network (FPDN) have run workshops called 'Our Way Planning'. This workshop helps services improve the way they support First Nations people with disability.

Recommendation 34:

First Nations peoples and organisations that represent them can say what they want and need. They need money to be strong organisations.

Recommendation 35:

Disability support workers need to learn about providing services to First Nations people with disability. First Nations people should be the teachers. The NDIS Commission should say when services must train their staff, and there needs to be enough NDIS funding for this to happen.

Women and girls with disability

More very bad things happen to women and girls with disability than woman and girls who do not have disability. They can experience terrible violence from family, carers, or other people.

Sometimes very bad things happen to women in group homes, but people do not see it as violence. This is not right. For example, a woman with a disability in a group home had her private parts shaved by support workers. She did not ask them to do this. The support workers thought this was a healthy thing to do. But this is a type of abuse and is a bad thing to do to a woman.

Sometimes very bad things happen to women in their family home. Women with disability might be scared to report very bad things. They might be scared of losing their home if they complain. This is a very real thing to fear if there are no services that can quickly help a woman in an emergency.

In Victoria, the Disability Family Violence Crisis Response Initiative has been able to help some women with disability who have experienced violence in their home. They need to have the money to keep doing this work.

Recommendation 36:

Disability support workers need to learn about the very bad things that can happen to women and girls with disability. They need to know what is wrong. The NDIS Commission should say when services must train their staff, and there needs to be enough NDIS funding for this to happen.

Recommendation 37:

Money is needed so that people with disability can get housing and emergency help when very bad things are happening in their home.

Older people with disability

People with disability have more health problems when they get older than people without disability.

Many disability support workers do not understand the health problems of people with disability as they get older.

For example, some people with disability will get dementia earlier than people without disability. The support workers need to understand the early signs of health problems so they can get help for the person.

Sometimes people with disability who are older need more help to be active, otherwise they spend more time sitting or sleeping, which can make their health worse. Often there are not enough support workers at day services and group homes to help people keep active.

Disability support workers may need to learn new skills to help older people with disability. Too many older people with disability move out of their home into a nursing home because the disability support workers are not given the skills or time to give the help that the person needs. For most people, it is better to get old in your own home, than to go to a nursing home.

Recommendation 38:

Disability support workers need to learn about getting older with disability. They need to learn about health problems, when to get help, and how to support the person. The NDIS Commission should say when services must train their staff, and there needs to be enough NDIS funding for this to happen.

6. Ways to support people, families, friends, and the disability workforce

Supporting families and friends

Family and friends are important to everybody. Family and friends of people with disability are important. They can help to make sure the person is safe. They can help the person be well. They can make sure the person's rights are respected. The person with disability can talk to family and friends if they are worried.

People with disability who do not have family and friends are at greater risk of very bad things happening to them. They may always have to rely on people who are paid to look after them.

Many of the complaints that come to the Disability Services Commissioner come from families who are worried. They see when someone is not happy. They see when people are not getting along.

Families need support too. Families can get tired and stressed if they must complain and fight for the rights of the person with disability. They can feel pressured to make decisions for the person with disability.

Some families get support from advocacy services.

Some families organise groups of people called a Circle of Support or a Microboard. These are groups of people who will think about the person with a disability. They will help to plan for the person. They will help to know that the person is happy and well. We think these groups can be very helpful for people with disability.

Recommendation 39:

Money is needed to help people have Circles of Support or Microboards. They may need training in working with the person with a disability to make decisions about their life.

Making disability support workers safer and more skilled

Disability support workers play a huge role in supporting people with disability.

There are some big problems with the disability support worker group in Australia. Some disability support workers do not have enough training to do a good job. Some disability support workers work alone and do not see good workers or have their work checked. Many disability support workers do not have a full time or part time job with their service. They are only called in to work when they are needed, and they may not know the people with disability well. Many disability support workers are paid poorly. Lots of disability support workers leave their job after a few months or year.

Disability support workers can be very stressed and busy. We have met workers who have had to help five people with disability to get up in a short time, or to eat their meals at the same time.

Not having enough staff increases the risk of very bad things happening. When there is not enough staff more accidents happen. This is because people do not get the support that they need.

Disability support workers need managers who see their work. They need time to think about how to do good work. They need guidance if they are not doing their job properly. They need to meet with their manager to talk about their job. They need training about the rights of people with disability.

A small number of staff deliberately do very bad things. They do not do their job properly. They do not get watched enough to make sure they work safely.

The NDIS Commission is writing rules about disability support workers. The rules will help people know what training disability support workers need.

We think that it is important that disability support workers have training in the following areas:

- Person-centred care
- Communication supports

- Positive behaviour support
- Supported-decision making
- End of life care
- Health promotion
- Support for particular groups (e.g., First Nations people, women, older people with disability).

The NDIS Commission should decide when the training must be done by all managers and disability support workers. Some training might not be needed in some places (e.g., training in women's needs would not be needed in a house of men).

Many disability service providers have said that they are doing less training now because the NDIS does not give them enough money to train the staff properly. They have said that there have been less meetings between disability support workers and their managers because there is not enough money.

Recommendation 40:

Disability support workers and their managers need to learn about the human rights model of disability. People with disability can say what should be in the training and be involved in the training. The NDIS Commission should say when services must train their staff, and there needs to be enough NDIS funding for this to happen.

Recommendation 41:

NDIA needs to look at the money that is needed by disability support services. There needs to be enough money to do all the things that the NDIS Commission says needs to be done and enough money for making a good disability workforce.

Making disability service providers better

A group home is a home for people with disability. A group home is also a workplace. There needs to be a balance between home and workplace. Sometimes there is too much focus on the workplace and not enough on the home. This kind of place is not good for anyone.

Sometimes there needs to be a big change in what disability service providers do. Sometimes good things are happening in the house, but bad things are happening in the offices of disability service providers. This can lead to people feeling bad about working in an organisation. It can lead to very bad things happening.

The NDIS Commission has an auditing program. This means someone will come into a service and ask the person with a disability or their family about what their service is like. While we think this is a good idea, we want to know that the person is asking good questions, that really gather good information about what is and is not working. We do not want them to just tick boxes. We want them to talk about better ideas.

We did a project called 'Building safe and respectful cultures'. It was about stopping abuse from happening. We made a group for talking to each other. There were people with disability, family, disability support workers, and managers in the group. Lots of the people felt like it was hard for them to make things better.

The disability support workers and management wanted more ideas on how to do things better in their organisation.

We learnt that having everyone talk to each other could help to make the organisation better. Everyone had to listen to each other: they had to listen to little worries and big worries. They had different sorts of meetings together to listen to each other and come up with good ideas.

Listening better to each other helped to make a better disability service.

Recommendation 42:

The NDIS Commission, service providers, people with disability and their families should look at our report and think about more ways to create better disability services and supports.