

The Disability Royal Commission and People with Intellectual Disabilities

Plain English summaries

In 2024, the journal Research and Practice in Intellectual and Developmental Disabilities (RAPIDD) published 2 special editions about the Disability Royal Commission and people with intellectual disabilities.

You can find the 2 special editions here:

<https://www.tandfonline.com/toc/rpid20/11/1>

<https://www.tandfonline.com/toc/rpid20/11/2>

The editorials and commentaries have been written as plain English summaries. 6 of the papers were presented at the ASID NSW one day conference in Sydney on 28 November, 2024.

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Introduction – Reading and reviewing Australia’s Disability Commission Report and its impact on people with intellectual disabilities.

Christine Bigby and Alan Hough

The Australian government set up an enquiry into the abuse of people with disabilities. It was called the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. We call it the DRC. The DRC started in 2019. The DRC wanted to find ways to prevent abuse of people with disabilities. They also wanted to find out how to better include people with disabilities in communities. The DRC had six Commissioners. Two people with disabilities were Commissioners. No one with an intellectual disability was a Commissioner. There was one adviser with an intellectual disability.

The DRC heard from a lot of people. They included people with disabilities, self-advocates, service providers, families, government people and researchers. They held 33 public hearings. Some people told the DRC in private what had happened to them. The DRC paid for some research to be done. In September 2023, the DRC wrote a large report. It is 12 volumes long. It is 40 centimetres high. Some of the report is in Easy English. You can find all the reports on the DRC's website: <https://disability.royalcommission.gov.au/>.

The report described the abuse of people with disabilities. It was hard to read about this. The report made 222 recommendations about many things that should change.

These included:

- Laws about rights.
- Disability services.
- Education services.
- Employment services.
- Health services.
- Training of staff.
- Community attitudes.

The Commissioners did not agree about everything. Some wanted to close group homes, special schools, and Disability Enterprises very soon.

Some recommendations are important for people with intellectual disabilities. But the DRC missed important things.

The Australasian Society for Intellectual Disability (ASID) publishes a journal called RAPIDD. The journal editor (Chris Bigby) and a guest editor (Alan Hough) asked people to

write about the parts of the DRC that interested them. The journal published 23 papers about the DRC and people with intellectual disabilities. You can read these on the journal website. Most of the papers are hard to understand for many people. Hilary Johnson and the authors have written short summaries of the papers in plain English.

Bigby, C., & Hough, A. (2024). Reading and reviewing Australia's Disability Commission Report and its impact on people with intellectual disabilities. *Research and Practice in Intellectual and Developmental Disabilities, 11*(1), 1–8.

<https://doi.org/10.1080/23297018.2024.2319365>

‘Old Problems and Old Solutions’ Snapshots of the Disability Royal Commission and people with intellectual disabilities.

Christine Bigby and Alan Hough

RAPIDD published 23 papers on the DRC and people with intellectual disabilities. We read all the papers. We thought about what they said. The papers looked at different topics. These included education, group homes, and rural services. They all said the DRC said some important things. But they said it could have done better for people with intellectual disabilities. They said that the recommendations:

- Were too much about law, policy and regulations. These may not affect the quality of services. They may not help people with intellectual disabilities get their rights. Only 68 of the 222 recommendations were about things that would directly help people with intellectual disabilities.
- Did not say new things. Did not find new solutions.
- Looked too much at bad things. Did not think about things that worked well. Did not learn from the good things. Did not insist that good things should happen. For example, that the government must help all mothers with intellectual disabilities.
- Did not look at things that only affect people with intellectual disabilities. Instead they included people with intellectual disabilities with others who were not like them.
- Did not look at the real causes of problems. For example, did not think the problem of unskilled workers may be because of the way services are funded.

We suggested the reasons for these things. Why the DRC did not do better.

- It thought only about individual rights. It did not think about families or staff.
- It thought too much about reporting of what services are doing. This makes a lot of paperwork. We know paperwork is not always good. Paperwork can get in the way of good support.
- Its approach was not suited to the task it had to do.
- It did not look at other ways of thinking. For example, about relationships, or what is similar for other disadvantaged people.
- It used the social model of disability to promote rights. It did not apply new thinking from the Human Rights model of disability. This is a new model. Only a few countries understand it yet. We must learn how to apply it to people with intellectual disabilities.
- It did not look at how the NDIS might do better.

The DRC cost a lot of money. It cost \$527.9 million. Was it a good use of money? Other reports and changes have happened since. The government took a long time to respond. It has only accepted 13 recommendations. It will consider others later. We will not know the impact of the DRC report for many years.

Bigby, C., & Hough, A. (2024). “Old problems and old solutions”: snapshots of the Disability Royal Commission and people with intellectual disabilities. *Research and Practice in Intellectual and Developmental Disabilities*, 11(2), 145–159.

<https://doi.org/10.1080/23297018.2024.2353269>

How neoliberal individualism led the Disability Royal Commission astray.

Jennifer A. Clegg and Richard Lansdall-Welfare

This paper talks about how an old policy idea took the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC) up the wrong path. Jennifer and Richard who wrote this paper (the authors) say that people at the DRC came up with recommendations that fit a way of thinking called neoliberalism.

Neoliberalism is a bit complicated. It was created 80 years ago at the end of the 2nd world war. It was to stop any powerful country doing awful things to any large group of people it disliked. At that time people thought protecting individual rights and choice was the way to stop it happening again. Indeed, focusing on individual rights has helped many people with disabilities. But other parts of neoliberalism have created problems. It started out as a policy about money, saying that governments should not design or run services. It said the government's job is to help private businesses develop services so people have plenty of choice. It said the businesses have to compete with each other. This can keep the services cheap for customers. The businesses are inspected and have to follow rules that the government thinks are right.

The people who thought up neoliberalism were successful in spreading their ideas. Services for people with disabilities are now run as neoliberal markets across much of the world. These markets have major problems. But once everybody thinks the same way, even when they are not the most useful ideas, doing anything different is difficult.

Many of the recommendations made by the DRC are about running a market that makes choice happen. This fits into neoliberalism. The authors argue this creates four problems:

- To choose a service, people need information about it. So, instead of spending money on training and paying staff well, huge amounts of money are spent on inspectors and inquiries. Some also goes on Accessible Information reports that few people read or understand.
- It takes up time if staff need to collect lots of data for the inspectors on what people with disabilities do. Then staff have less time to help the people they support. People with intellectual disabilities need time with staff to do things and make friendships.
- Competition makes services run as cheaply as possible. That keeps staff wages low so many staff leave after a short time for a job that pays better. Staff need longer relationships with people to know how best to support them.

- Inspectors and the DRC believe there is one approach that ‘good’ services should provide, so they can check if staff are doing it. They say behaviourism is best. Research shows this is not true. Behaviourism ignores people’s emotional lives and relationships. But services that do anything else are marked down by inspectors.

Three important things are also missing from the DRC’s neoliberal recommendations:

- If the focus is only on the individual with an intellectual disability, people who support them get ignored. Parents and staff also need support when they become frightened and upset.
- Prosecution is necessary when people are treated cruelly. But we need more than prosecution to change things. Ending cruelty also needs positive intervention. This can be supporting exhausted parents, opening safe places where people can meet, and building community connections. But the DRC does not recommend this.
- Neoliberal policy is shaped by what advocacy groups tell governments. Many advocates say they want a job, which fits well with a neoliberal belief that work solves social problems. But people with intellectual disabilities do not all have the same needs. Work may not be one of their goals. The DRC did not say how people can have a full life without going to work. Sometimes people with intellectual disabilities like to have time together. Here they can learn from each other and have fun. The DRC did not talk about this.

The authors argue that the DRC did not have the right answers for people with intellectual disabilities. The best services create different approaches to suit different people. Some help people with their emotional development so they might not get upset. Designing services the neoliberal way does not lead to the range of support necessary for people who have different kinds of intellectual disabilities. It does not help the staff and families who work or live with them.

Clegg, J. A., & Lansdall-Welfare, R. (2024). How neoliberal individualism led the Disability Royal Commission astray. *Research and Practice in Intellectual and Developmental Disabilities*, 11(2), 302–317. <https://doi.org/10.1080/23297018.2024.2373944>

Recommendations of the Disability Royal Commission fail to recognise families, siblings in particular, as natural lifelong supports for people with intellectual disabilities.

Kate Strohm

The Disability Royal Commission (DRC) said families are important to keep people with disabilities safe and to live full lives. Families are even more important for people with intellectual disabilities. Families include parent and siblings (brothers or sisters). The research tells us that people with intellectual disabilities may find it hard to develop relationships with others. Family members are often their only close relationships. Families can provide supports for a very long time. When a child is young, they are looked after by their parents. As they grow older siblings may help more. It is not always easy for families. Some families are very stressed. Families need to be well supported. This lets them give the person with an intellectual disability a happy and safe life, both at home and in the local community. The DRC does not talk about what families need to support their family member well. They do not talk about the challenges families have and how to help families. The DRC talks more about paid workers not natural supports.

Kate writes in this paper about siblings. She says they are very important. They can be there for lifelong relationships. They can help disabled siblings be included at school and in the community. They can give them practical care and keep them safe. They can give and get back love, and they can have fun together. They can teach the community to see the person not just the disability. Siblings have challenges too. They might find it hard to live their own lives. They might feel they have to take care of their sibling all the time. They need supports too.

The DRC writes about the importance of informal supports. Informal supports are people who help out and give advice. Families are informal supports. The DRC only talks about families as carers, rather than focusing on the importance of relationship. Families can be a person's strongest advocate. The DRC recommends more advocacy support but not through families. This is surprising. The DRC listened to a lot of stories about the importance of families in giving informal supports to make their family members life better. This includes changing community attitudes. Families are important to help with changing community attitudes. The DRC seems more interested in legal changes around guardianship. This will not help informal supports.

Kate says there are 6 things the DRC did. They:

- Did not talk much about the importance of families. They talked more about changing laws rather than improving family supports. These supports need to start from when the baby is born.
- Did not talk much about the good things families do. None of the DRC recommendations were about helping families.
- Did not talk about siblings. Siblings give different informal supports than parents do.
- Did not talk about how to support siblings. It can be hard to be a sibling. Peer support groups have been helpful for siblings to manage the challenges.
- Said to use a human rights approach. Kate said the DRC needs to look at the extra help people with intellectual disabilities need. This might be to help a person communicate how they want to live their life. The DRC did not talk about how families might take a role in changing community attitudes.
- Did not talk about balancing the rights of people with intellectual disabilities with those of others. Not all families find it easy to live with a person with an intellectual disability. Sometimes it is hard if the person has challenging behaviours. People who live in group homes may also find this hard.

Kate said the DRC missed an opportunity to give families extra support. She said more research is needed. This research should look at what helps or doesn't help family members support people with intellectual disabilities. They should be supported to be happy, safe and included in the community.

Strohm, K. (2024). Recommendations of the Disability Royal Commission fail to recognise families, siblings in particular, as natural lifelong supports for people with intellectual disabilities. *Research and Practice in Intellectual and Developmental Disabilities*, 11(2), 287–301. <https://doi.org/10.1080/23297018.2024.2364340>

Don't judge a book by its cover: What the Disability Royal Commission can do for parents with intellectual disabilities.

Rhiannon Derzsi, Kathy Ellem and Morrie O'Connor

Kate, an Aboriginal woman from New South Wales, told the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation (DRC) what happened to her and her children. Her story is sad. Her children were taken away by child protection services. She felt she was not listened to. The service did not work with her to help her keep her children. The DRC said they wanted to know what help First Nations Australian parents needed. They said two things need to change:

- The state and territory government assessments need to change. Some of the assessments look at parenting capacity – the ability to provide love, care and safety for children. These need to be co-designed together with parents of children with disabilities. They need to fit with the cultural backgrounds of the parents.
- First Nations Australians under 5 years old need to be assessed with a tool ASQ-TRAK. This might help them get an early intervention plan through the National Disability Insurance Scheme (NDIS).

Rhiannon, a parent with an intellectual disability and advocate, read Kate's story. She felt the DRC should have done more for all parents. She said:

- Parents with intellectual disabilities need specific supports. They get their children taken away by child protection services.
- Parents with intellectual disabilities are people with human rights and need to be listened to.
- Child protection officers should follow policies and procedures.
- Child protection officers should use simple clear language and make sure the parents understand what they say or write.
- When child protection take children away they need to talk with the parents. They need to tell them what is happening with their child. They need to tell them:
 - About the child's carers.
 - What is happening with their schooling.
 - Their diagnosis.
 - Everything about their child.

Derzsi, R., Ellem, K., & O'Connor, M. (2024). Don't judge a book by its cover: what the Disability Royal Commission can do for parents with intellectual disabilities. *Research and Practice in Intellectual and Developmental Disabilities*, *11*(2), 225–233.

<https://doi.org/10.1080/23297018.2024.2384699>

A lost opportunity: Did the Disability Royal Commission let down parents with intellectual disabilities and their children?

Susan Collings, Margaret Spencer and Renee Mills

There are over 21,000 Australian parents with intellectual disabilities. The research says these people often face poverty, housing issues, and social isolation. Also, these parents have more contact with child protection service than any other parents. This is not always good. There are many things in our society that make their life hard. These are things like:

- Not getting a diagnosis and the supports that come with it.
- Partner and family violence (women with intellectual disabilities have a high risk of violence in their lives).
- Ableism (negative attitudes against people with intellectual disabilities). This can change the way services are provided. People might not get the support they need to make decisions or understand what is happening to them.
- Structural violence. This is about taking away children from parents with intellectual disabilities. Parents with intellectual disabilities are not seen as equals in society. A child protection officer may fear the child might be in danger because a parent has an intellectual disability.

The DRC looked at what happens to people over their lifetime. This is a life course framework. They looked at times in a person's life such as early childhood or adolescence. They did not use being a parent as a time point.

The DRC looked at the experiences of First Nations people with disabilities with child protection and out-of-home care. The DRC did not include all parents with intellectual disabilities. They only made recommendations for First nations people. The DRC missed an opportunity to improve lives for all parents with intellectual disabilities.

The authors of this paper wanted to see more recommendations for all parents with intellectual disabilities. This included changes in the systems of our society such as:

- Ways to help young women and parents get reproductive justice. That is to understand more about sexual health, pregnancy, and early intervention services.
- Help with disability advocacy. There was no mention of this. Disability advocacy helps parents with disabilities find their way through complex issues. This might include dealing with lawyers and the Children's court.

- Putting in place laws and regulations to help all parents with intellectual disabilities and their children be safe. These might include making sure pregnant women get help when they need it and maternity support.
- Ways for parents with intellectual disabilities to make complaints. Most of these parents are not getting support through the NDIS. It is difficult for them to complain about services.
- Ways to lessen the personal and structural violence against people with intellectual disabilities.
- Changes to child protection services so more children can stay with their parents. This might include stopping ableism and changing parenting assessments.

Collings, S., Spencer, M., & Mills, R. (2024). A lost opportunity: did the Disability Royal Commission let down parents with intellectual disabilities and their children? *Research and Practice in Intellectual and Developmental Disabilities*, *11*(2), 211–224.

<https://doi.org/10.1080/23297018.2024.2384047>

The role of parents in facilitating safe, quality, inclusive education for students with intellectual disabilities: the position of the Disability Royal Commission.

Glenys Mann, Lynsey Kennedy-Wood and Linda Gilmore

The DRC looked at how to make good, safe, and inclusive schools. They talked to lots of parents who have children with intellectual disabilities. They made recommendations. Parents are important. They help their children get good schooling. Parents are very important for children with intellectual disabilities. These children may need extra help.

Parents do 3 main things. They:

- Choose the school for their child. This might be a special or mainstream school.
- Know their child well. They can work with the teacher to get the best for their child.
- Speak up for their child. Parents say when things are not good for their child. They try to make it better.

The DRC made recommendations about these 3 things. These were:

- **The choices parents make.** Parents can choose a special or mainstream school. Not all commissioners on the DRC agreed that special schools are good. Parents might choose a special school for several reasons. Sometimes it is because they cannot get the help they need in a mainstream school. Sometimes they have difficulties with the staff and teachers. Parents have different views about what is best for their child.
- **Parents' involvement in what happens in schools.** Schools are better when teachers and parents work together. This does not always happen. The DRC were worried that parents were not listened to. Teachers argued with parents. Parents felt bad. They felt pushed out of the system. Parents felt they were not told what was happening and had no rights.
- **Making complaints.** Parents said it was difficult to complain when things went wrong. These things included bullying, using restrictive practices, and teachers having low expectations of students. Parents got very tired trying to make things better for their child. Parents were worried about complaining. They did not want their child to have any negative outcomes.

The DRC made 7 recommendations about these 3 things. Glenys, Lynsey, and Linda who wrote this paper think they should have made stronger recommendations. They thought:

- Parents need to be able to choose a mainstream school for their child. Special schools might not be safe as they use restrictive practices. Parents do not choose special schools for the best educational outcomes. Choosing a mainstream school is not always easy. Parents need to know their child will be welcome there. Mainstream schools are not always inclusive of all children. Teachers will not learn skills to include all children if there are two types of schools.
- Supporting teachers to work together with parents is important. The DRC recommended different laws. They needed to talk about how to build better relationships between schools and parents. They could use the Partnership Model.
- Parents need help to know how to be good advocates. It is not just about making complaints. Complaints happen when things cannot be worked out between the school and the parents.
- The DRC did not find out anything new. We know that parents need more help to get their voice heard. We know more work is needed to develop good parent-teacher relationships.

Mann, G., Kennedy-Wood, L., & Gilmore, L. (2024). The role of parents in facilitating safe, quality, inclusive education for students with intellectual disabilities: the position of the Disability Royal Commission. *Research and Practice in Intellectual and Developmental Disabilities*, 11(1), 107–120. <https://doi.org/10.1080/23297018.2024.2337756>

A critique of the Disability Royal Commission's approach and recommendations for educational inclusion in schools.

Teresa Iacono

The Disability Royal Commission (DRC) looked at the school education system for people with disabilities. They wanted to find out if people with disabilities were included. This means they got the same education as other students. Inclusion also means students are valued and feel they belong. In Australia everyone can go to mainstream schools. Not all mainstream schools are welcoming. Not all schools give students the supports they need. Students with severe disabilities (that includes students with intellectual disabilities) sometimes go to special schools. These are separate from mainstream schools. Some mainstream schools put children with disabilities in a special unit on the school site. This separates them from other students.

The DRC looked at the research and heard from parents, people with disabilities, educators and researchers. The evidence was not good. They found students with disabilities (especially those with severe to profound intellectual disabilities) had many bad experiences. These included:

- Students with disabilities do not get the same educational opportunities. This has been happening for a long time. Some students with NDIS individual funding are separated out. They do not join in with the rest of the class.
- Students are ignored. They may also experience violence.
- Students with challenging behaviour get restrictive practices. These practices may hurt students.
- Students have no rights. Things that are done to students might be more about keeping staff safe. The actions are not focussed on keeping students safe.
- Attitudes and actions hurt students. These happen in mainstream and special schools.

The evidence is not new. Government has made laws and policies but there has been little change. This is very sad for the students and families. Recommendations have made the student the problem. Recommendations should look at what lets bad practices happen to these students.

The DRC focussed on the type of school. Not everyone in the DRC agreed on what to do. Some said Special Schools should be closed. Some said there should be Special units in mainstream schools. The problem of abuse needs more solutions.

The DRC made recommendations. These include:

- Remind everyone of Australian laws. Students have a right to a free education. They have a right to the same education as peers without disabilities. They have the right to be in the same class as peers without disabilities. Schools must provide the supports a student needs.
- Policies to help parents. Parents don't always get the information they need. They need clear information about school processes. This might include how to enrol. The policies need to be easy to understand.
- Getting complaints heard. To set up complaints offices. There needs to be somewhere to complain not connected with the school.
- Schools need to collect information about when they exclude students. Also, they need to collect information on what sort of supports students need. This is important information for government. It can help with future funding and resources.
- Increase staff knowledge and skills. Staff need to know how to include all students. This might be students who have little or no speech or from different cultural backgrounds.
- No more special schools. Some members of the DRC think you cannot be included if you go to a special school. Other members think Special Schools should continue so that students with disabilities and their families can choose.

Teresa who wrote this paper says the DRC did not say anything new. They talked about models of support that are old. An example is More Supports for Students with Disabilities. These models were trialed across Australia over 10 years ago. Some were good for students. They need more research. The DRC did not say more research is needed.

Teresa thinks the DRC missed some important things. These include:

- Models of inclusion. One model looks at students' rights to get what they need. There is a model that tells teachers how to change what they do to fit the student. It includes allied health professionals.
- Looking at collaboration. There is evidence that says if parents and professionals work together they can help the student learn.
- A focus on inclusion in mainstream not special schools. Inclusion is more about staff attitudes and skills. It is more about working together – as teachers, parents, and

allied health professionals. It is about changing what you do for each child. It is about how you do things as a team.

Teresa thinks a change needs to happen for students with disabilities. It needs more than DRC recommendations. It needs students, parents, carers, and educators to talk about what inclusion really means. This will help in knowing what to do.

Iacono, T. (2024). A critique of the Disability Royal Commission's approach and recommendations for educational inclusion in schools. *Research and Practice in Intellectual and Developmental Disabilities*, *11*(2), 160–175.

<https://doi.org/10.1080/23297018.2024.2377993>

“Enough with the closed doors adorned with inclusion and diversity statements”: an examination of the Disability Royal Commission’s position regarding special schools.

Glenys Mann

The Disability Royal Commission (DRC) looked at education for people with disabilities. They focussed on inclusive education. They looked at the two types of schools in Australia. These are mainstream schools and Special schools. They wanted to know if going to one type of these schools improved the lives of students with disabilities. Going to the best type of school means: they got a good education, felt included in the community, were free from harm and abuse and had the same rights as peers without disabilities.

All children have the right to go to a mainstream school. Most people think you will get a better education and have friends with children without disabilities in a mainstream school. Some parents think a Special school is better for their child. You must have an intellectual disability to go to a Special school. There has been a discussion over many years about whether we should have Special schools. Surprisingly, there has been an increase in the number of Special schools in Australia. This goes against the voice of the UNCRPD. The question of which school is better is very complicated. There are a lot of things involved. The DRC looked at information from other investigations into inclusive education. There have been many in Australia. They talked to parents, educators, and researchers. They held public meetings. They worked very hard to find an answer. They found good and bad things about both types of schools. They found these things about Special schools:

- Some parents said their children were safe and had a sense of belonging.
- Special schools had more resources than mainstream schools.
- Some students did get harmed. This also happened in mainstream schools.
- Special schools do not give a student the best education. There are low expectations of student abilities.
- There is neglect. There are more restrictive practices in segregated settings.
- Students from Special schools are less likely to go onto mainstream employment.

The 6 Commissioners on the DRC could not agree about closing Special schools. 3 Commissioners felt parents should have a choice. They saw Special schools as being only one part of a child’s life. The children could still be part of the local community. They did not agree that what the UNCRPD said was law in Australia.

3 Commissioners wanted to close Special schools. They said Special schools made students feel different to other children. Children without disabilities looked down on them. The Special schools did not give students the same work opportunities as mainstream schools. Special schools did not help them develop friendships with peers who could support them to be safe in the future. They said the Australian laws and the UNCRPD were against Special schools. They set up a timeline to get rid of Special schools.

The DRC looked at a lot of information. All the Commissioners could not agree on what to do. Glenys who wrote this paper said this might be because of their different life experiences, their professions and how they look at the world. This affected their attitudes and what they thought was best for students with disability. Glenys said there was no clear definition of the words inclusion and segregation. The Commissioners did not agree about what each word means.

Glenys said if we keep Special schools, there will be risks. If there are no changes in Special schools, that will not be good for students. It will not be good for changing community attitudes about disability.

If we get rid of Special schools, there will be risks. Some parents will feel they have no choice. Making a big change like this will need to happen slowly. Students who move to mainstream schools will need to get the same resources and supports they got in Special schools. It will not be easy for everyone. Glenys says if we are going to get inclusive education there needs to be only one type of school. All children attend that school, and supports are in place for all students. 2 things need to happen. These are:

- Getting a law that says children with disabilities need to go to local mainstream schools.
- Finding a way to help mainstream schools work out how to provide the things students with disabilities will need.

Glenys says it is time to give inclusive education a go. This means all children go to one school. Places in Canada, Italy and Portugal are doing this. They can show us how to do this.

Mann, G. (2024). "Enough with the closed doors adorned with inclusion and diversity statements": an examination of the Disability Royal Commission's position regarding special schools. *Research and Practice in Intellectual and Developmental Disabilities*, 11(2), 176–192. <https://doi.org/10.1080/23297018.2024.2387636>

A flawed model or weak implementation? A critical review of the approach to group homes taken by the Royal Commission.

Christine Bigby

The Disability Royal Commission (DRC) looked at what makes a good life for people with disabilities. It looked at what happens to people who live in group homes. It looked at:

- What is the group home model or way of living? Are there different ways for people with intellectual disabilities to live?
- How do people get support in their homes?

The DRC collected a lot of information. This was from people living in group homes, their families, and advocates. The DRC also got information from the government, service providers, and academics. A lot of this information was about bad experiences.

Some people said all group homes were bad. They called group homes mini-institutions or segregated and closed environments. People saw them as bad places because those who lived there could not choose to live anywhere else. Also, because many people in group homes had no contact with people outside their homes.

The DRC heard other reasons for bad experiences in group homes. These were about the staffing and management of group homes. They included poor support from staff in group homes. This was due to a lack of training and supervision. Also, because management didn't follow up on complaints.

There was some evidence that group homes can be good places to live. This happens when skilled staff provide good support. The DRC heard little about what people liked about group homes.

There was little information about places to live that were not group homes. There are other places to live. But few other places are for people with intellectual disabilities who need a lot of help.

The DRC's report said:

- Active Support and Practice Leadership would improve group homes.
- There should be other places to live than in group homes. They should help people with intellectual disabilities to be more independent and connect with the community.
- It was important that the people who own the group home are separate from the people who provide the staff.

The DRC Commissioners did not agree about what should happen. Some wanted to stop building group homes. Some wanted to close all group homes in 15 years. They all wanted people to have more choice about where to live.

The DRC's report missed some important things.

- There was no definition of a group home.
- There was little information on better options than group homes for people with severe or profound intellectual disabilities.
- That bad practice could happen in other places, as well as in group homes.
- There was a big problem with staff training.
- There was no evidence that alternatives to group homes were better.

The DRC's recommendation might worry people in group homes about their future. Families and advocates may worry about funding for the group homes.

The DRC saw it is important to change things about group homes. This is so that people with disabilities can live their lives without abuse and neglect. The DRC's report may be important to make the government make changes.

The NDIS review also looked at group homes. It said group homes should not have more than four people. It said the quality of support, wherever a person lives, is important. It introduced a new term: Housing and 24/7 support.

Bigby, C. (2024). A flawed model or weak implementation? A critical review of the approach to group homes taken by the Disability Royal Commission. *Research and Practice in Intellectual and Developmental Disabilities*, 11(1), 9–28.

<https://doi.org/10.1080/23297018.2024.2316290>

Mainstream housing and the Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability.

Ilan Wiesel

The Disability Royal Commission (DRC) said that people with disabilities have great difficulty finding somewhere to live. The DRC said that people with disabilities should be one of the first people (priority group) to get help with housing. This is good policy but there are many people who need housing. There are not enough houses for everybody. Many houses are not accessible for people with disabilities. It can be very expensive to rent a home. There are many people with intellectual disabilities who are homeless. People who are homeless without support are more likely to have violence in their lives.

The DRC put forward some recommendations. Ilan who wrote this paper made some comments about the recommendations.

- People with disabilities should be a priority group to get help. This should be said in all national housing plans. Also in homelessness plans. People with disabilities should be named in strategies, policies, and action plans.
- The DRC looked at ways to help with homelessness. They suggested using a lot of support as in the Housing First model. Ilan says sometimes this model might not be right for people with disabilities. Putting people with disabilities to live with many other people without extra support may lead to more violence. They would need extra help to make sure this did not happen.
- There are building standards that make houses accessible for people with physical disabilities. Not every state has the same standards. The DRC says New South Wales and Western Australia need to have standards like other states. More houses would then be accessible.
- There needs to be more social housing for people with disabilities. This can be done by changing policy about who is a priority. It also needs to be easier for people with disabilities to ask for help with housing. Some of the houses need to change. People who have difficulty moving around need it to be easy in their house. Getting physical changes made to houses is not always easy. Ilan says the waiting list for social housing is very long. If someone is offered a house but cannot get through the front door, they might not get another chance at a house. A more supportive approach to social housing is needed.

- Residential tenancy laws need to change. People with disabilities who rent a house often do not know how long they can stay in the house. They need laws that say they cannot be thrown out of the house for no reason. The landlord needs to have a good reason. Ilan says Australian laws are not good for renters, particularly private renters.
- There needs to be improvements and checks for quality and service standards in boarding houses. Boarding houses are often not safe or pleasant places for people with disabilities. The DRC says boarding houses need to:
 - Do better support planning.
 - Keep records of the support people get.
 - Make sure complaints are heard.
 - Help people find independent advocacy services.

Ilan says the DRC report is a very good start. He agrees with many of the recommendations. He wants to see more housing for homeless people, but with better support for those with disabilities. He wants to see more social housing built. He wants to see national and state funding to build more houses that people with disabilities can live in.

Wiesel, I. (2024). Mainstream housing and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. *Research and Practice in Intellectual and Developmental Disabilities*, 11(1), 29–38. <https://doi.org/10.1080/23297018.2024.2335506>

The Disability Royal Commission and the regulation of disability service provision.

Alan Hough

The Disability Royal Commission (DRC) made recommendations about the rules, regulations, and policies in the disability service system. Regulations are like laws. The DRC looked at what the NDIS is doing and made recommendations for changes. The DRC had to make difficult decisions. It is important to have some rules that help provide good services. The rules must be understood and followed. Rules and policies can help services improve what they do.

The regulation system is complicated. Regulators, like the NDIS Quality and Safeguards Commission, work out what they think are the best rules. Service providers and workers do not need to be registered (have an agreement) with the NDIS. The NDIS has a code of conduct (how to behave at work) – this says what all service providers and workers should do. Those services which are registered have more and different rules to follow than those who are not registered. Alan writes about some of the key issues for the NDIS Commission. These are from the DRC recommendations. These are:

- **Complaints.** The NDIS gets lots of complaints. But people with intellectual disabilities do not make many complaints. It is hard for them to complain. The DRC said we need to find ways to hear the voices of people with intellectual disabilities. They recommended connecting people with advocacy organisations and increasing community visitors into accommodation settings. They also say people who respond to the complaints need to have good communication skills. They need training in talking with people who have little or no speech.
- **Registration.** The DRC wants all disability support workers to be registered. There would be background checks on workers' history. There would be training opportunities. All workers would learn about safeguarding and how to give a good service.
- **Enforcement.** The DRC said organisations and workers should be punished if they do something wrong. Alan says this needs to be done carefully. In most cases, when people do the wrong thing they need a chance to get it right next time.
- **Resources.** The DRC made some recommendations about the use of restrictive practices. They suggested the NDIS might need more resources to change regulations. Alan says there is not enough detail on how to use restrictive practices differently. We need ways to protect human rights.

- **Quality auditing.** The NDIS has rules about how services do things. They audit services (check what the service is doing) to see if they are following standards for registration. The DRC said auditors need to know information about what has happened in services to do a better job.

Alan says the DRC did not recommend any big changes to the NDIS. There will be some financial resources needed in changing approaches. Involving people with an intellectual disability takes time and money. The NDIS Commission needs to do this. The NDIS needs to focus on more than finding the problems. It needs to help organisations and workers provide good support.

Hough, A. (2024). The Disability Royal Commission and the regulation of disability service provision. *Research and Practice in Intellectual and Developmental Disabilities, 11*(1), 39–52. <https://doi.org/10.1080/23297018.2024.2312530>

Adult safeguarding in Australia after the Disability Royal Commission.

John Chesterman

The Disability Royal Commission (DRC) made recommendations about adult safeguarding. These recommendations will change what we do. John who wrote this paper uses the words adult safeguarding to mean:

- Adult guardianship laws and practices.
- Other laws and practices. These are to make sure people with intellectual disabilities have rights and are safe.

The DRC recommended independent adult safeguarding agencies in every state or territory. These agencies would explore reports of adults with disabilities in the community who may be abused or neglected. They would not do individual public guardianship work. We do not know what these agencies will look like. The Australian Law Reform Commission suggested these agencies would be a new independent statutory body or a departmental unit, and they could do more things than the Public Guardians or Public Advocates. John says they might use the agencies in South Australia and New South Wales as examples.

The DRC recommended new words for guardian and guardianship legislation. Sometimes people with disabilities need help making important decisions. These might be personal or about money. There needs to be someone who knows how to help a person make a decision. This is supported decision making. The decision will be based on what the person wants to happen or their “will and preferences”. People with disabilities can get a guardian or administrator to help them. The DRC suggested to use the word representative instead of guardian. John thinks this is OK but sometimes the word attorney is needed.

The DRC recommended 10 supported decision making principles. Research talks about 2 sorts of decision making: substitute decision making and supported decision making. Substitute decision making is making a decision for the person. Some researchers think there should only be supported decision making. Not everyone agrees. The DRC said substitute decision making should be used as a last resort. Not everyone agrees.

The DRC recommendations are mostly in line with what the Australian Law Reform Commission recommended. This is good. John says the recommendations can be done. Some of them have already started. Some of them will need help from advocates to make happen. There are 2 challenges to make the changes happen:

- States and territories have been asked to make changes, but not the Commonwealth government. This might make change more difficult to happen.
- The recommendations will not immediately make people safer. Because of this they may not seem urgent. They will need advocates to push for the changes to be made.

There is still more work to be done to help the DRC recommendations happen.

Chesterman, J. (2024). Adult safeguarding in Australia after the Disability Royal Commission. *Research and Practice in Intellectual and Developmental Disabilities*, 11(1), 53–62. <https://doi.org/10.1080/23297018.2024.2316291>

Supported decision-making and the Disability Royal Commission.

Shih-Ning Then and Christine Bigby

The Disability Royal Commission (DRC) said that supported decision-making is important for people with disabilities to get their rights. Supported decision-making means giving people the support they need to make choices and decisions. This is important for people with intellectual disabilities as well as other people, including those with dementia and mental health problems. When supported decision making does not happen others make decisions for people.

The DRC gave a lot of attention to supported decision-making. They listened to a lot of people talk about it. This included people with intellectual disabilities, researchers, and families. They paid advocacy services to include those who had difficulties communicating. People said,

- Co-design and leadership by people with disabilities about supported decision-making is important.
- Supporting people to make decisions takes a lot of time.
- Supporters need training. This includes families.
- Workers in disability services must know how to do supported decision-making.
- Workers in other services must know how to do supported decision making. This includes workers in health, justice, shops and banks.
- Some people need supported decision making about many decisions. It is not just about big decisions.

Everyone told the DRC that they thought supported decision making was a good idea. But people had different ideas about it.

The Commission paid for research on why, and how, to do supported decision-making. The researchers said supported decision making should be for everyone. It must include people with severe intellectual disability. They said everyone has preferences. People express preferences in different ways. Supporters must try to understand what a person wants. This is called knowing their 'will and preferences'. If someone else decides, they must take notice of the person's will and preferences.

The DRC agreed with the researchers that supported decision making should be for everyone. They said a 'principled approach' to supported decision making was important. The DRC

made many recommendations about supported decision making. Most of these were about changing the ‘guardianship’ law. Guardianship is when someone is appointed to decide for a person with disability. The DRC said even a guardian must take notice of the person’s will and preferences. You should only ignore a person’s preferences if the person is in great danger. These DRC recommendations were like those of a 2014 report on law reform. The DRC also said supported decision-making is not one size fits all. People have different needs. For example, supported decision making may not fit First Nations culture.

The authors Shih-Ning and Christine said the DRC could have done more. They worried that the DRC looked mainly at changing law. The DRC wrote about wanting to do more about supported decision making. But there were no recommendations on how to make supported decision making happen in all service systems. Or about changing how supporters work every day to support decisions. Or how supporters can work out the hard things about supported decision making. This was disappointing.

We know supporters of people with intellectual disabilities need training in supported decision-making. We know supported decision making takes time to do it well. We don’t know how people will find the resources needed to do this. The DRC did not say anything about people who need help in end-of-life planning. Shih-Ning and Christine said we need to know how to help people get the skills they need to support people with intellectual disabilities to make daily decisions. The DRC did not tell us this.

Then, S. N., & Bigby, C. (2024). Supported decision-making and the Disability Royal Commission. *Research and Practice in Intellectual and Developmental Disabilities, 11*(1), 86–106. <https://doi.org/10.1080/23297018.2024.2330961>

Research to reduce the use of restrictive practices: a response to recommendation 6.38 of the Disability Royal Commission.

Monica Cuskelly and Nicola Crates

The Disability Royal Commission (DRC) took a human rights view based on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The DRC heard that many people are not free to do what they want because of restrictive practices.

Restrictive practices are things such as:

- Seclusion (people are kept away from other people).
- Physical constraint (holding someone down so they can't get up).
- Pharmacology (giving someone medicine to change their behaviour).
- Mechanical restraint (special clothing that limits movement).
- Environmental restraint (putting locks on cupboards or doors).

Restrictive practices are put in place for people with disabilities to keep themselves or others safe. This is done when someone has a behaviour of concern or challenging behaviour. This is when they repeatedly do something that hurts themselves or other people. If someone has a restrictive practice they should have a behaviour support plan. This plan is written using a framework of Positive Behaviour Support. Positive Behaviour Support aims to reduce behaviours of concern. Then, it aims to remove restrictive practices.

The DRC think the research evidence for using Positive Behaviour support to reduce restrictive behaviours is not strong. They want to fund more research. Monica and Nicola who wrote this paper think more research is good but want different research. They say we need to look at why we think restrictive practices reduce behaviours of concern. They say:

- Reducing behaviours of concern does not always result in taking restrictive practice away.
- Taking restrictive practices away sometimes results in reducing behaviour of concern.

Monica and Nicola looked at the research on restrictive practices. They write about all the different things that can change the results for restrictive practices. One of these is the staff. They say it is important to know why people use restrictive practices. The DRC research does not include this.

Monica and Nicola write about the data collected on restrictive practices. They think it needs to be different. The data does not tell us what works well. They write about the Positive Behaviour framework. They say it is not one thing but many strategies. The DRC research will need to include details about the strategies to know what works well. Monica and Nicola write about the importance of working out the best research design. It is hard to make sure the research does what it is supposed to do in this research. People with intellectual disabilities live in different places. The staff and environments will be different. This adds to the difficulty of the research.

Monica and Nicola want the DRC research to happen. They want to make sure the research:

- Focuses on reducing the use of restrictive practices.
- Includes looking at staff and the organisations involved.
- Asks for professional opinions about the research design before the research starts.
- Involves people with an intellectual disability in the design and how the research is measured.

Cuskelly, M., & Crates, N. (2024). Research to reduce the use of restrictive practices: a response to recommendation 6.38 of the Disability Royal Commission. *Research and Practice in Intellectual and Developmental Disabilities, 11*(2), 234–250.

<https://doi.org/10.1080/23297018.2024.2349036>

Positive Behaviour Support is effective when implemented correctly: a response to “Restrictive practice – A pathway to elimination” (Spivakovsky, Steele, & Wadiwel, 2023).

Trent Carberry, Simon Wardale, Sarah Hutchison, Susan Lackey and Maria Vassos

The Disability Royal Commission (DRC) funded a group of researchers to look at the research on restrictive practices and Positive Behaviour Support. One of the questions they asked was if Positive Behaviour Support helps reduce or gets rid of restrictive practices. The researchers said that Positive Behaviour Support was not effective in reducing restrictive practices.

The people who wrote the paper (authors) do not agree with those researchers. The authors say that Positive Behaviour Support is used all over the world. There is research to say that it can be effective. Effective Positive Behaviour Support requires training. Positive Behaviour Support is a method of teaching people more appropriate behaviours. Some challenging behaviours are ones where a person hurts themselves or others. In Australia, restrictive practices are only used if a person hurts themselves or others. Restrictive practices can only be approved when there is a behaviour support plan. The plan looks at:

- What are the challenging behaviours?
- Why they might be happening?
- What can be done to help the person have a better life?
- How to do these things in their home/workplace/community.

The authors looked at the research on Positive Behaviour Support in disability settings. The authors say we need to know what people are doing when they do Positive Behaviour Support. They need to be using a Positive Behaviour Support framework.

For Positive Behaviour Support to work well there needs to be:

- Well trained staff.
- A detailed assessment of what behaviours are happening and why.
- A clearly written behaviour support plan.
- A plan that tells the support worker what to do. These actions need to be person-centred.

There is evidence that Positive Behaviour Support works well when a well written plan is done well. Australian evidence suggests that many plans are not written well. We have a tool that can assess the quality of a support plan.

Most research only looks at the results for a few people. These are called case studies. These show good results. Currently, a Positive Behaviour Support plan is required to use restrictive practices in Australia. This means many plans are written to get agreement to use restrictive practices. These might not be good Positive Behaviour Support plans. The authors suggest it would be better if Positive Behaviour Support plans were not done only for restrictive practice agreements. They say the focus of Positive Behaviour Support should be on good outcomes rather than compliance with legislation.

The authors know we don't always do Positive Behaviour Support well in Australia. There are online resources to help workers know how to do this well. We need to give workers more skills. Positive Behaviour Support should be used to help people with challenging behaviours.

Carberry, T., Wardale, S., Hutchison, S., Lackey, S., & Vassos, M. (2024). Positive Behaviour Support is effective when implemented correctly: a response to “Restrictive practice – A pathway to elimination” (Spivakovsky, Steele, & Wadiwel, 2023). *Research and Practice in Intellectual and Developmental Disabilities*, 11(2), 251–264.

<https://doi.org/10.1080/23297018.2024.2391804>

Restrictive practices in community services for people with intellectual disabilities at risk of behaviours that challenge: insights and omissions of the Disability Royal Commission.

Petra Björne

This paper looks at what is needed to provide safe and comfortable small group homes for adults with intellectual disabilities. These homes should be places where people are supported to make decisions, be involved in the community and have a full life. The research says this does not always happen. Group homes can be places in which people are abused or mistreated. Restrictive practices might happen in these homes. Some researchers say restrictive practices can be bad. They discriminate against people with disabilities.

The Disability Royal Commission (DRC) think restrictive practices are used too often. Restrictive practices are against a person's human rights. Restrictive practices can be used when someone has a behaviour of concern. Behaviours of concern are also called challenging behaviour or behaviours that challenge. These behaviours are when someone repeatedly does something that hurts themselves or other people. It can also be repeatedly breaking things. These behaviours are communicating something. Sometimes it is difficult to know what. It might be frustration, anger, pain, sadness or boredom. It might be something or someone in their past or present. It might be about the people they live with or the staff that support them. You need to look at the person and the things around them. This helps you to understand why these behaviours happen. The staff in the environment might want themselves or the person to be safe. They might think restrictive practices are good. A behaviour support plan is written for the staff to follow. This tells them when to use restrictive practices. Restrictive practices are things such as:

- Seclusion (people are kept away from other people).
- Physical restraint (holding someone down so they can't get up).
- Chemical restraint (giving someone medicine to change their behaviour).
- Mechanical restraint (special clothing that limits movement).
- Environmental restraint (putting locks on cupboards or doors).

Research says that some restrictive practices do not work and may cause pain or fear. This might lead to more bad memories for the person. Restrictive practices need to be a last resort

– that means the last thing we try for a person. We need to look first at how we can make a person's life safe and happy.

The DRC recommended having less restrictive practices. This is good. Petra who wrote this paper agrees there needs to be more research. We need to collect better information about what happens and why it happens. The DRC wants to reduce restrictive practice beyond disability settings. It want this in health education and justice. This is a good thing.

Petra says the issues of restrictive practices are complex. The DRC recommendations may not be enough to help reduce restrictive practices. They want to do 3 things:

- They want to get more information on behaviour support plans. The research is not clear about the use of restrictive practices. We do not know if a behaviour support plan will reduce restrictive practices. Petra says there is a lot that can go wrong:
 - The behaviour support plan is not clear.
 - The behaviour support plan does not support the staff.
 - The restrictive practice may cause the person more emotional or physical pain.
- They want better laws on using restraint as a last resort. Even if this happens, they will be difficult to use in reality.
- They want quality services. They think services will be of a better quality without restrictive practices. Petra says lots of things make a quality service. Just taking away restrictive practices will not be enough. A lot of changes in the system are needed.

Some people from the DRC wants to get rid of group homes. They see that a lot of bad things like abuse and neglect happen in group homes. Researchers talk about what can happen when group homes are the only option for people with disabilities. The staff might develop the wrong ideas. Staff may think residents and themselves are safer with restrictive practices. They might want to use restrictive practices more often. The DRC wants to give people with disabilities a choice of where they live and who they live with. This might not be possible. Finding somewhere to live is difficult. It might be better to look at how to help make group homes safer and happier places to live.

Petra says we need to look at the research on getting quality care into group homes. The research says we need:

- A person centred approach (looking at what each individual needs).
- Asking people with disabilities what they want.
- Organisational policies and resources.

- Staff and management training with ongoing support in daily practice.
- Values shared by management and all staff.

Petra says we need to look at a framework to support quality care. This is a capable environment framework. This includes:

- Communication support for social interactions.
- Giving choice and control in everyday situations.
- Involving people with disabilities.
- Making sure staff have the skills needed.
- Health support.
- Good organisational management.

A good quality service should be the main goal. This may mean less restrictive practices. If staff have good relationships with the people they support there may be less behaviours that challenge. More research is needed on how to make and keep long term capable environments.

Björne, P. (2024). Restrictive practices in community services for people with intellectual disabilities at risk of behaviours that challenge: insights and omissions of the Disability Royal Commission. *Research and Practice in Intellectual and Developmental Disabilities*, 11(1), 63–74. <https://doi.org/10.1080/23297018.2024.2333804>

The Disability Royal Commission on National Disability Insurance Scheme (NDIS) workforce issues: avoiding the root causes?

Caroline Alcorso and Yumi Stanet

The workforce (staff who work with people with disabilities) was not a focus of the Disability Royal Commission (DRC). The workforce is important for everyone. Both researchers and people with disabilities talked about difficulties with staff support. In the end, the DRC made recommendations about improving the workforce. Trained, high quality staff are needed to support people with intellectual disabilities and complex needs. Getting and keeping well trained staff is very difficult. The workforce has changed since the NDIS. Disability support workers are 90% of the workforce. It is no longer regular full-time work. The workforce is mostly casual and unskilled. This does not make for a high quality, safe environment for people with intellectual disabilities. Staff leave the workforce because of:

- High workload and low pay.
- Feeling burnt out.
- Too much paperwork and not enough time.
- Bad workplace culture and issues with management.
- Not enough skill development.

The DRC talked about 6 workplace issues that led to recommendations.

- **Work value and pay rates.** This is a need to look at workers who get paid differently (less) under a home care pay award. Support workers do complex work, and they need to get paid more. The DRC said workers need to be heard. The authors of this paper think more should be said about employees and unions as stakeholders.
- **Worker screening and registration.** Most workers (90%) are not registered. Not everyone needs to register. The DRC think if everyone has to register it would help the status of the profession. The authors think it is more important to provide high quality training for the workforce. It is also unlikely workers would register as it is not easy or quick. Registration might make some people go and work elsewhere. The authors think it would be better for:
 - All workers to have proper screening checks.
 - All workers to get high quality training.
 - Training to be at basic and specialist levels.
 - Leave and training skills to be moved across workplaces.

- **Support coordinators and behaviour support practitioners.** There are not enough support coordinators or behaviour support practitioners. Support coordinators help people to use their plans and find the supports they need. The DRC recommends having more support coordinators and fund more time for them to support people. Behaviour support practitioners write positive support behaviour plans to reduce restrictive practices. They are not well trained and do not always write good plans. DRC recommended on-the-job training and things that might attract more people to work in those roles. The authors think that not anyone can be a behaviour support practitioner. These roles demand a high level of knowledge and skill in supporting people with behaviours of concern. The authors think that providing funding for support coordinators and behaviour support practitioners will not fix the current problem. These people need experience of working in the disability sector. If they move roles to somewhere else they will leave gaps. The authors think there needs to be a better strategy that increases these specialist roles but does not take away workers from the disability sector.
- **Workforce development.** The DRC said that staff lacked skills, supervision and mentoring. They recommended training and frontline support. The authors think these are good recommendations but may not work. They say the overall funding and process systems need to change. Only then could the workforce get job security and high-quality training.
- **Qualifications.** Disability workers do not need any formal qualifications to do their job. This is unlike workers in aged care who need a qualification. The DRC did not recommend qualifications for disability support workers. The authors are surprised at this. They think if workers all had a qualification this would be helpful. There would need to be other system changes to reduce staff turnover and increase professionalism.
- **NDIS disability support worker cost model.** The NDIS has worked out how much face-to-face time a support worker has in every hour. The model does not allow much time for administration, training, staff meetings, and supervision. This lack of time reduces the quality of support that workers provide. The DRC did not talk about changing the NDIS cost model. The authors think this was a political decision. If the cost model does not change, it will be difficult to increase the quality of the workforce.

The authors suggest bringing together key people to discuss the DRC recommendations and how to move forward. They think the discussion should be people with disabilities and key people from all sectors including staff, employers, and government.

Alcorso, C., & Stamet, Y. (2024). The Disability Royal Commission on National Disability Insurance Scheme (NDIS) workforce issues: avoiding the root causes? *Research and Practice in Intellectual and Developmental Disabilities*, *11*(2), 193–210.
<https://doi.org/10.1080/23297018.2024.239596>

Why was allied health missed? A critical examination of the recommendations of the Disability Royal Commission for allied health professionals working with people with intellectual disabilities.

Laura Hogan and Abby Watt

The Disability Royal Commission (DRC) explored the health system. They looked for any unmet health needs that could harm people with cognitive disabilities. The DRC used the words cognitive disabilities. They said this includes people with intellectual disabilities. Research shows that people with intellectual disabilities have more complex health difficulties than the general population. The DRC looked at how the health system worked, such as staff skills and workforce training. They mostly talked to people with a medical or nursing background. This was surprising. Allied health professionals also help people with intellectual disabilities with health issues. Allied health professions include occupational therapists, speech pathologists, physiotherapists, dietitians, and social workers. The DRC found that allied health professionals can reduce some health barriers. These barriers include difficulties with communication, having falls, or death from swallowing difficulties.

The DRC wanted to know about the skills and knowledge of healthcare professionals to support people with cognitive disabilities. They said that the NDIS has helped many people get allied health support. Unfortunately, people in rural and remote areas still struggle to get these services. The DRC made several recommendations to improve healthcare delivery. Some of these are for medical and nursing workforce. Laura and Abby who wrote this paper looked at the recommendations. They wanted to see if they would improve allied health support for people with intellectual disabilities. They looked at 4 issues:

- **Putting people with intellectual disabilities together with people with cognitive disabilities.** Laura and Abby are concerned that this is not a step forward for people with intellectual disabilities. In 2021, the Australian government developed a 10-year plan to improve health outcomes for people with intellectual disabilities. This includes:
 - Finding the key things healthcare students need to know when supporting someone with an intellectual disability.
 - A national centre of excellence in intellectual disability health.

Research says people with intellectual disabilities have specific health needs. Support for them has started to happen in the 10-year plan. Some specific needs might get

missed if people with intellectual disabilities are put together with people with cognitive disabilities.

- **Allied health education.** The DRC wants to add information on working with people with cognitive disabilities to university courses. They think this will help allied health students prepare for work. This idea is based on examples from other countries where doctors and nurses specialise in working with people with cognitive disabilities. This does not work for allied health professions in Australia where there is no speciality for working with this group.

The DRC also wants allied health students to have more placements with people with cognitive disabilities. Most allied health professionals who support this group work under the NDIS. The NDIS does not fund the time to supervise the students on placement. The DRC did not talk about NDIS funding.

- **Health workforce.** The NDIS has seen a change in the workforce. In 2023, 50% of all allied health profession worked alone. Before the NDIS they worked in teams with other allied health professionals. They had professional development and supervision. This does not happen under the NDIS. There is a risk of allied health professionals not having the skills to support people with intellectual disabilities. The DRC said multidisciplinary teams that worked together would be helpful. The DRC did not talk about how the NDIS could make this happen.
- **Funding and access to services.** People with mild intellectual disabilities do not have access to NDIS funding. The DRC did not talk about these people. These people need allied health support. People in rural and remote areas have difficulties finding allied health professionals. The DRC talked about getting a provider of last resort.

Laura and Abby are concerned the DRC did not look at the difficulties people with intellectual disabilities have in getting allied health support. Most people with intellectual disabilities get funding support from the NDIS. It is important to look at how professions are funded. This might help people with intellectual disabilities get better health outcomes.

Hogan, L., & Watt, A. (2024). Why was allied health missed? A critical examination of the recommendations of the Disability Royal Commission for allied health professionals working with people with intellectual disabilities. *Research and Practice in Intellectual and Developmental Disabilities, 11*(2), 318–330. <https://doi.org/10.1080/23297018.2024.2382414>

The findings of the Disability Royal Commission: the relevance for people with intellectual disabilities in rural areas.

Stuart Wark

The Disability Royal Commission (DRC) looked at what happens for people with disabilities all over Australia. This includes people who live in cities and those who live in the country, outside big cities. The DRC talked to people in rural, regional, and remote areas. This included places like Townsville and Alice Springs. We know people who live in places outside cities have more difficulty getting services. This paper looks at what the DRC says about people who live in rural areas. This summary uses the word rural to cover the rural, regional, and remote areas the DRC talks about. Some rural areas have more people with disabilities than those in the cities. Sometimes the DRC talked to people through the internet. This was hard for people with intellectual disabilities and some voices were not heard. The Easy Read report of the DRC's recommendations did not talk about people from rural areas. But the DRC did talk about people from rural areas in their larger report. Stuart who wrote this paper looked at all the recommendations. He said many of the recommendations were important for all people with intellectual disabilities wherever they lived. Only 14 of the 222 recommendations were focussed on people who live in rural areas. Stuart talked about these 14 recommendations for people with intellectual disabilities.

- Getting services.
 - Difficult to get transport to take people to services.
 - Governments asked to give better supports for people who get in trouble with the police.
 - Governments asked to give better supports for people who live in violent homes.
- Who gives the support?
 - There is a lack of services. There is an urgent need for a provider of last resort. That is someone who can give people the services they need.
- How to get more expert staff.
 - Ask NDIS Quality and Safeguards Commission to help get more behaviour support practitioners to work in rural areas.
 - Find behaviour support practitioners to help First Nations people in remote areas.

- First Nations people.
 - Ask NDIS Quality and Safeguards Commission to set up a First Nations Unit.
 - Ask NDIA to get more community connector programs.

The DRC Easy Read report needed more information. It is important that Easy Read helps the reader understand difficult words. Some people with intellectual disabilities felt left out. The DRC Easy Read report did not mention that people live in different places such as rural, regional or remote.

Stuart said the recommendations focussed more on people who lived far away – in remote communities. This was good for those people. But there are more people who live closer – in rural and regional places. There need to be more recommendations for these people. Some of these people might be helped in the NDIS review in December 2023. This review had some recommendations like the DRC's report.

Wark, S. (2024). The findings of the Disability Royal Commission: the relevance for people with intellectual disabilities in rural areas. *Research and Practice in Intellectual and Developmental Disabilities*, 11(1), 121–132. <https://doi.org/10.1080/23297018.2024.2340573>

Exploring the Disability Royal Commission's views on the inclusion of people with intellectual disabilities in the decision -making and governance of disability services.

Bernadette Curryer, Michelle Donnelly and Kim Roots

One of the aims of the Royal Commission into Violence, Abuse and Neglect and Exploitation of People with Disability (DRC) was to find ways that people with disabilities can be included in the community. One way is to ensure people with disabilities can provide leadership to service providers and community organisations. Many disability services have boards. People with a range of skills and knowledge sit on boards. Their roles on the board are to ensure the organisation provides quality services. Boards do governance. Governance oversees the culture and practices of organisations. Governance practices must be fair, meet the service user's needs and keep people safe. This paper looks at DRC's recommendations on including people with intellectual disability in governance roles.

The DRC saw that some good things were happening in some disability services. These included:

- Service users providing input on service design and delivery.
- Formal committees of service users that report directly to boards.
- Active recruitment of people with disabilities to board and leadership roles.

The DRC wanted more of these things to happen. The authors of the paper said the DRC did not make specific recommendations about:

- How to change the make-up of boards and governance practice so more people with disability are included.
- How to include people with intellectual disabilities in governance and leadership roles.
- The steps needed for disability services to develop inclusive governance.

The authors of this paper know that not everyone wants to be on a board. There are many ways to provide leadership in organisations and be heard. "Nothing about us without us" means people with disabilities need to be involved in decisions that might affect their lives. This often does not happen for people with intellectual disabilities. People with intellectual disabilities may need a lot of support to give input to service.

There is evidence that listening to people with intellectual disabilities is helpful to boards. It can improve the quality of their services. The DRC did not say how organisations will be encouraged and supported to change. It also did not say how support for people with intellectual disability will be provided. Organisations need to know what they must do to be more inclusive.

Curryer, B., Donnelly, M., & Roots, K. (2024). Exploring the Disability Royal Commission's views on the inclusion of people with intellectual disabilities in the decision-making and governance of disability services. *Research and Practice in Intellectual and Developmental Disabilities*, 11(1), 133–144. <https://doi.org/10.1080/23297018.2024.2342417>

Start with a vision: our thoughts on the Disability Royal Commission's Recommendations for employment for people with intellectual disabilities.

Paul O'Dea, Michael Cherry, Kathy Ellem and Morrie O'Connor

This paper was written by Paul, Michael, Kathy and Morrie. They looked at the employment recommendations from the Disability Royal Commission (DRC). Paul and Michael shared their thoughts as self-advocates. Kathy and Morrie asked them questions as supporters. Kathy wrote down what was said.

Paul and Michael talked from their experiences of paid work. Some of the things they said about people with intellectual disabilities were:

- They should be paid the same as people without disabilities.
- They should be supported to learn new skills.
- They should be given opportunities for promotion.
- They should be in friendly workplaces where they feel respected and safe.

The people who wrote this paper all talked about the DRC's recommendations. They agreed it was important that:

- People with intellectual disabilities should be involved in developing a new Disability Employment Services Model. People with intellectual disabilities often feel like they are on the outer and their needs are not considered. The DRC calls people on the outer 'edge users' and say services do not think about their needs.
- There need to be goals to employ people with intellectual disabilities in the public sector. There are lots of different jobs they could do.
- People with intellectual disabilities should get paid more. This might be expensive for the government. They don't want people to lose their jobs.
- People with intellectual disabilities should be able to choose where they work. Some might like to work in places like Australian Disability Enterprises. There should be a bigger range of choices.

O'Dea, P., Cherry, M., Ellem, K., & O'Connor, M. (2024). Start with a vision: our thoughts on the Disability Royal Commission's Recommendations for employment for people with intellectual disabilities. *Research and Practice in Intellectual and Developmental Disabilities*, 11(2), 278–286. <https://doi.org/10.1080/23297018.2024.2377995>

Reducing the risk of false guilty pleas: how has the Disability Royal Commission addressed this pathway to wrongful conviction for people with intellectual disabilities?

Glenys Holt

Some people with intellectual disabilities say they are guilty to things they did not do. These are called false guilty pleas. A plea is what you make when the court asks you if did something (an offence) that the police say you did. You might say guilty or not guilty. If you plead guilty when you are not guilty this is a false guilty plea. Doing this means some people will go to prison when they should not. In Australia we do not know how many people make false guilty pleas. We know from other countries that people with intellectual disabilities make false guilty pleas. The court can change their minds about the person being guilty if they find out they made a false guilty plea. This called an overturned conviction. Glenys who wrote this paper looked at what the Disability Royal Commission (DRC) said about the risks of false guilty pleas. She also looked the DRC's recommendations to see if they will help people with intellectual disability in the pleas process.

There are many reasons why people make false guilty pleas. There is very little research in Australia about this. We do not have a record of who or how many people had a wrongful conviction. It might not be many people. But there are too many people with intellectual disabilities in the criminal justice system. The DRC talked to people with intellectual disabilities to find out what happened to them in the justice system. The DRC said we need to know how many people with intellectual disabilities are in the criminal justice system. We need to know how many plead guilty or not guilty. We need to know about people with intellectual disability in prison.

Why do people with intellectual disabilities make false guilty pleas? These are some of the possible reasons:

- Their lawyer does not know they have an intellectual disability, or the offence is due to the person's disability.
- They do not understand what is said to them.
- They do not understand what will happen if they plead guilty.
- They are scared they will get indefinite detention if they say not guilty. This means going to prison, maybe for a very long time. Indefinite means no one knows when it will end.

- They have had a lot of interactions with police before. They might think no-one will believe them.
- They do not understand the court or legal system.
- They are only thinking of what happens immediately. Not what pleading guilty might mean in the future.
- They more readily say yes to things (acquiescence). They say what they think people want them to say. They want to please people.
- The police think they are guilty. This might cause the person with an intellectual disability to do something that looks like they are guilty. An example would be running away from police.
- They think it does not matter what they say. They think they will be found guilty, whether they are guilty or not. They don't have any power.
- The courts are very busy. They like guilty pleas as the trial will be shorter. But this does not mean that the court wants people to give false guilty pleas.

The DRC recommended 2 things that are important for people with intellectual disabilities:

- People with intellectual disabilities should not be put into a prison indefinitely. Laws need to change. There needs to be a maximum time a person with an intellectual disability can be put into prison. At the moment, states and territories all have different laws.
- We should improve pre-sentencing court diversions. People with intellectual disabilities need to get help before their trial. Part of this is looking for a program that supports what the person might need. This might be getting assessed through the National Disability Insurance Scheme. They could give a person some support in the community.

Glenys agrees with these recommendations. She also thinks we need some good research. We need to collect detailed information on plea decisions. We need to know when pleas happen and what makes them happen. We also need more information on overturned convictions.

Holt, G. A. (2024). Reducing the risk of false guilty pleas: how has the Disability Royal Commission addressed this pathway to wrongful conviction for people with intellectual disabilities? *Research and Practice in Intellectual and Developmental Disabilities, 11*(2), 265–277. <https://doi.org/10.1080/23297018.2024.2372625>

Improving safety at home: responding to violence, abuse, and neglect of people with intellectual disabilities across environments and settings.

Sally Robinson

The Disability Royal Commission (DRC) wrote a report that looked at how to make lives safer for people with disabilities. Sally writes in this paper about the DRC's approach and recommendations. Sally looks at the recommendations for people with intellectual disabilities. She asks if the recommended research can lead to practical change in people's lives. She wants to know how we can change bad attitudes and practices towards people with a disability. We want a world where violence and abuse are not OK. We need to do more to change community attitudes.

The DRC talked with people and they read research about domestic and family violence. Their recommendations look at how to stop violence in disability service settings. Sally argues that not all people with intellectual disabilities live in disability service settings. People need help across a range of services if people are to live safely in the community. The DRC recommendations include to:

- Make better laws about domestic violence.
- Get better policy about fixing domestic violence.
- Add an action plan to the National Plan to End Violence against Women and Children.
- Make safeguards the same in each state and territory.
- Develop a national safeguard framework.
- Start a one-stop shop for people in violent situations. Here people with disabilities can find out what to do and someone will help them find the right place to go.
- Increase what community visitors can do.

These changes are good, but more is needed. The DRC know broad system change is needed. One thing the DRC wants is the Australian government to make a Disability Rights Act. This will keep people with disabilities safer. Sally says this is good but will be hard to make it happen. It needs lots of organisations and government bodies to come together. They will need to make policies and practices that work everywhere.

Sally says the research shows the lack of skilled staff to support people in complex situations. It is hard to find people who know about disability, violence and working with young children. Families with disabilities find it hard getting support through NDIS. It is even

harder when there is an emergency. Children and young people need to be supported. They may have different needs from their family.

Sally says new frameworks are needed for practical change. It is more than changing laws. We need to stop people from falling through gaps in the system. We need a system that is well connected. We need to stop making it hard for people with disabilities to get help when they need it. We need to include people with intellectual disabilities to look at what will make the community a safe place. We need their help to make it happen.

Robinson, S. (2024). Improving safety at home: responding to violence, abuse, and neglect of people with intellectual disabilities across environments and settings. *Research and Practice in Intellectual and Developmental Disabilities*, 11(1), 75–85.

<https://doi.org/10.1080/23297018.2024.2331575>