Inclusion Australia

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9 February 2024

Dear DSS Engage team,

Re: Australian Government response to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Inclusion Australia is the national peak organisation representing the rights and interests of Australians with an intellectual disability and their families. Founded 70 years ago in 1954, our mission is to work to make sure people with an intellectual disability have the same opportunities as people without disability.

Our strength is in our national representation and our connection to our community. We have a member organisation in every state across Australia, and a branch in the Northern Territory:

- Council for Intellectual Disability (CID)
- Parent to Parent (P2P)
- South Australian Council on Intellectual Disability (SACID)
- Speak Out Association of Tasmania (Speak Out)
- Victorian Advocacy League for Individuals with Disability (VALID), and
- Developmental Disability WA (DDWA).

These organisations work with hundreds of people with an intellectual disability and families, and represent some of Australia's most marginalised community members.

We were heavily involved in the work of the Disability Royal Commission throughout its life, preparing our own submissions, commissioning research, providing case studies, supporting witnesses, sharing information with our community, and providing accessibility advice to the Commission's team and its support services.

We are committed to working with the Department and the Australian Government to ensure there is a robust response to the Royal Commission's recommendations and that we collectively work towards the elimination of violence, abuse, neglect and exploitation of people with disability.

Thank you for allowing us extra time to finalise our response, please find our submission to this consultation attached. We warmly welcome further consultation about any of the recommendations raised in this submission.

Kind regards,

Catherine McAlpine
Chief Executive Officer, Inclusion Australia

Inclusion Australia

Australian Government response to the Disability Royal Commission

Submission to the Department of Social Services

Contents

Summary of priority recommendations from the Disability Royal Commission Final Report

Employment	
Recommendation 7.16 Priorities for inclusion in the new Disability Employment Services model	
Inclusion Australia: Additional reforms to implement as part of Recommendation 7.16:	• Ensure that everyone who wants employment support is eligible and referred for DES services, no matter how many hours they want to work. • Ensure all people with an intellectual disability who use the NDIS should automatically receive employment supports in their plan if they have an employment goal. • Replace Job Capacity Assessments with a strengths-based evaluation that focuses on what the person wants to do and the supports they need to do that. • Fund specific long term, DES support for older people with an intellectual disability who have either never worked in mainstream employment, have had long periods out of the workforce, or who want to explore other work options after working in an ADE.
Recommendation 7.17 Develop education and training resources for Disability Employment Services staff	
Recommendation 7.18 Establish specific and disaggregated targets for disability employment in the public sector	
Recommendation 7.19 Establish specific disability employment targets for new public service hires in agencies and departments	
Inclusion Australia: Additional reforms to implement as part of Recommendation 7.18 and 7.19:	• Set targets at each level of government for employment of people with an intellectual disability in their public sector disability employment strategies • Ensure all government departments and agencies—such as the NDIS, the NDIS Quality and Safeguards Commission and the Department of Social Services at the federal level—that directly work with people with disability set targets for employment of people with disability, including specific targets for people with an intellectual disability

	• Provide funding to local government, starting in regional areas, to facilitate the employment of people with an intellectual disability within local government directly. • Ensure DES works with local government and NDIS providers in regional areas to facilitate employment, particularly to meet the new employment targets.
Recommendation 7.29 Embed an ‘open employment first’ approach in the NDIS Participant Employment Strategy	
Inclusion Australia: Additional reforms to implement as part of Recommendation 7.29 and 7.30:	• Ensure access to Supported decision-making—including a significant investment in independent, accessible information about employment and support options—is resourced and implemented as part of all employment reforms. • Partner with disability advocacy organisations—especially those with specialist expertise in supporting people with an intellectual disability and developing Supported decision-making resources—to support the transition to inclusive employment. • Ensure ADEs are resourced to provide people with support and pathways to open employment if they change their mind about working in an ADE and/or gain more skills and experience and want to get a job in open employment. • Require ADEs to develop individualised employment plan for every worker and to undertake comprehensive data collection to quantify the number of people looking for open employment, including the extent to which individuals have access to Supported decision-making to make those choices.
Recommendation 7.31 Raise subminimum wages	
Recommendation 7.28 Improve information about wages and the Disability Support Pension	
Inclusion Australia: Additional reforms to implement as part of Recommendation 7.28	• Reform the income test for recipients of the DSP to better support people facing structural barriers to participating in the workforce, and to better recognise the fluctuating nature of a person’s ability to participate in paid employment. • Raise the income thresholds at which the DSP payment is reduced and lower the taper rate by which it is reduced once this threshold is reached.

Inclusive Housing

Recommendation 7.41 Group home reform

Recommendation 7.42 Improve access to alternative housing options

Inclusion Australia: Additional reforms to implement as part of Recommendations 7.41 and 7.42	• Invest in ongoing extensive and independent evaluation and dissemination of emerging best practice in home and living supports • Invest in a cost benefit analysis of home and living supports. • Ensure access to Supported decision-making—including a significant investment in independent, accessible information about employment and support options—is resourced and implemented as part of all housing reforms. • Partner with disability advocacy organisations—especially those with specialist expertise in supporting people with an intellectual disability and developing Supported decision-making resources—to support the transition to inclusive housing. • Ensure SDA and SIL providers are resourced to provide people with support and pathways to inclusive housing options if they change their mind about their home and living supports at any stage. • Ensure that specialist advocacy organisations are funded to provide independent decision support and independent accessible information to assist people to explore housing options.

Inclusive Education

Recommendation 7.1 Provide equal access to mainstream education and enrolment

Additional reforms to implement as part of Recommendation 7.1	• Ensure that students with disability eligible for either a special school or a mainstream school who require specialist school transport are provided access to this support as part of their NDIS plans. This should be implemented as a matter of urgency, given the previous agreement from states and territories ended in December 2023. As per the NDIS Review recommendation, the approach must include: ○ A national benchmark for service quality that is human rights based and designed in partnership with children and young people with disability, their families, special and mainstream schools, and DROs with specialist experience such as CYDA ○ A pre-condition that specialist school transport is available and accessible to eligible students who attend either or both special schools and mainstream schools.

<table>
<tr><th colspan="2">Accessible information and communication</th></tr>
<tr><td colspan="2">**Recommendation 6.1 A national plan to promote accessible information and communications**</td></tr>
<tr><th colspan="2">Guardianship</th></tr>
<tr><td colspan="2">**Recommendation 6.5 Objects of guardianship and administration legislation**</td></tr>
<tr><td colspan="2">**Recommendation 6.9 Representatives as a last resort**</td></tr>
<tr><th colspan="2">Supported decision-making</th></tr>
<tr><td colspan="2">**Recommendation 6.6 Supported decision-making principles**</td></tr>
<tr><td>**Inclusion Australia: Additional reforms to implement as part of Recommendation 6.6**</td><td>• Provide an additional investment in supports for those with **complex communication needs** as a priority to uphold the rights of those who face the biggest barriers to Supported decision-making and are more likely to lack other informal safeguards.</td></tr>
<tr><td colspan="2">**Recommendation 6.13 Information and education on supported decision-making**</td></tr>
<tr><td colspan="2">**Recommendation 6.14 Systemic advocacy to promote supported decision-making**</td></tr>
<tr><th colspan="2">Advocacy</th></tr>
<tr><td colspan="2">**Recommendation 6.21 Additional funding for advocacy programs**</td></tr>
<tr><td colspan="2">**Recommendation 6.22 Improved data collection and reporting on met and unmet demand for disability advocacy**</td></tr>
<tr><td>**Inclusion Australia: Additional reforms**</td><td>• Ensure that improved mechanisms for data collection are designed in partnership with independent advocacy organisations, including DROs, and are used to develop funding arrangements that reflect true community need.</td></tr>
<tr><th colspan="2">Informal supports</th></tr>
<tr><td>**Inclusion Australia: Additional reforms to implement as part of the**</td><td>• Work with DROs to establish and sustainably fund strategies to build informal supports/natural safeguards in the lives of people with disability, prioritising people with an intellectual disability and those</td></tr>
</table>

government's response to Volume 6 in relation to safeguarding	residing in closed settings, who are less likely to have informal supports in their lives.
Health	
Recommendation 6.24 Improve implementation planning and coordination for the cognitive disability health capability framework	
Recommendation 6.25 Expand the scope of health workforce capability development to include all forms of cognitive disability at all stages of education and training	
Recommendation 6.29 Improve specialist training and continuing professional development in cognitive disability health care	
Recommendation 6.33 Develop specialised health and mental health services for people with cognitive disability	
Restrictive practices	
Recommendation 6.36 Immediate action to provide that certain restrictive practices must not be used	
Recommendation 6.35 Legal frameworks for the authorisation, review and oversight of restrictive practices	
Recommendation 6.38 Strengthening the evidence base on reducing and eliminating restrictive practices	
Inclusion Australia: Additional reforms to implement as part of Recommendation 6.38	• Invest in research activities co-designed with people with an intellectual disability and their families—with an emphasis on including people residing in segregated or closed settings such as group homes, ADEs and criminal justice settings—to increase the evidence-base in relation to behaviour support and the elimination of restrictive practices.
Behaviour support	
Recommendation 10.24 Improved access to behaviour support practitioners	

Inclusion Australia: Additional reforms to implement as part of Recommendation 10.24	• Require that the person is meaningfully involved in the development of their own support plans through access to Supported decision-making • Ensure behaviour support plans promote trusting relationships between the person and their supporters • Increase the accessibility of behaviour support plans and ensure that they are devised in formats that make sense to the person
Transport	
Additional recommendations to implement as part the government's response to the Disability Royal Commission	• Include the rights of people with an intellectual disability in the Disability Standards for Accessible Public Transport 2002 • Ensure all information and communication relating to public transport must be freely available in inclusive formats such as Easy Read • Implement mandatory testing of all new public transport systems by people with intellectual disability, and ensure people are paid for doing so • Ensure public transport is safe for all people, including people with an intellectual disability • Enforce greater accountability and enforcement of the Standards is urgently needed across all states and territories.

A note on terminology

The Disability Commission uses the term 'cognitive disability', which is an umbrella term that describes the effects of several conditions, which includes intellectual disability.

A pathway to an inclusive Australia

As the *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (the Disability Royal Commission) has clearly demonstrated, an inclusive Australia is contingent on:

The independence of people with disability and their right to live free from violence, abuse, neglect and exploitation.[1]

It has been established through the thousands of testimonies of evidence given at public hearings, private sessions, community engagements, in submissions, and through its robust research program that inclusion is most evident where:

An individual is made welcome, where they feel welcome, where they know they belong, where they know they are safe, and where their voice is heard and acted upon … it is where people live free from poverty, in close personal relationships with others, where they have friends and advocates and where they are free to express their philosophical/religious beliefs, sexual and cultural identities, that people can live a quality life free from violence, abuse, neglect and exploitation.[2]

Barriers to inclusion

Yet it was also established by the Disability Royal Commission that experiences of violence, abuse, neglect, and exploitation are frequently and disproportionately experienced by people with disability. There is also evidence that those experiences are more likely to (though do not solely) take place in segregated settings, separate from the community.[3]

We also know that people with certain disability types are more likely than others to experience life in such settings. That cohort is predominately people with cognitive impairment,[4] including people with an intellectual disability. This is even more likely for people with complex needs, including those with high communication support needs.[5]

A snapshot of evidence drawn from the findings of the Disability Royal Commission demonstrates the ways experiences of violence, abuse, neglect and exploitation—the very antithesis of an inclusive life—significantly impact people with an intellectual disability, as shown in the diagram below.

Lessons from the Disability Royal Commission

People with an intellectual disability are more likely to:

Live in a group home

Almost half of Specialist Disability Accommodation (SDA) participants have an intellectual disability as their primary disability (42%).

Be unemployed, or work for subminimum wages

People with an intellectual disability are less likely to be employed full-time than other people with disability and are more likely to be employed in an Australian Disability Enterprise, with only 15% having a job in open employment on a full wage.

Suffer from financial hardship

Among people with disability, people with an intellectual disability are among the least likely to receive an income from a wage through employment and report higher rates of financial hardship.

Rely on government payments as a primary source of income

72% of people with an intellectual disability's main source of income comes from a government pension or allowance, usually the Disability Support Pension.

Be a victim of violence and abuse

67% of people with an intellectual disability have experienced violence since the age of 15. The rate is higher among women with an intellectual disability.

Be overrepresented in the criminal justice system

People with an intellectual disability, especially First Nations people, are significantly overrepresented at all stages of the criminal justice system, from police contact and arrest, through to court processes and correctional settings.

Be detained for longer periods if found unfit to stand trial

When a person with an intellectual disability does not have access to appropriate supports, they are likely to be detained for longer periods than had they been found guilty and sentenced accordingly, and are at risk of being detained indefinitely.

Be subject to restrictive practices in response to 'behaviours of concern'

People with disability are subject to the greatest use of restrictive practices in segregated settings such as group homes, where people with an intellectual disability are more likely to reside.

Be overprescribed psychotropic medications

In some cases, the number and dosage levels of psychotropic medications administered to people with an intellectual disability are so significant, they constitute abuse.

Experience seclusion and solitary confinement in youth detention and prisons

Isolation amounting to solitary confinement is over-used in criminal justice settings, especially youth detention, in which people with an intellectual disability are overrepresented.

Have limited access to legal aid as victims of crime

People with an intellectual disability are likely to experience a range of barriers to access to justice, such as support to give evidence with proper legal representation.

Have limited access to quality healthcare

People with an intellectual disability experience significant barriers in accessing safe and quality healthcare, and experience higher mortality rates, increased incidence of preventable illness and more frequent hospital admissions.

Source: The Disability Royal Commission findings, see appendix a for full breakdown of references

Economic cost

These inequities and significant human rights breaches are associated with a high economic cost to government.

Research commissioned by the Disability Royal Commission[6] examined economic cost to governments as a result of violence, abuse, neglect and exploitation of people with disability. To do this, researchers examined the gaps in outcomes[7] between people with and without disability and estimated the proportion that can reasonably be attributed to systemic failure and neglect. That is, areas of unequal service delivery, unequal access to economic opportunity, or systemic discrimination.

To estimate the economic cost, the researchers calculated the amount of cost that would be avoided if violence, abuse, neglect and exploitation ceased, and by extension, Australia succeeded in making the Disability Royal Commission's vision of an inclusive Australia a reality. It includes the cost that would be avoided if:

- People in the community ceased to commit acts of interpersonal violence, abuse, neglect and exploitation towards people with disability, and
- Issues of systemic failures and neglect of people with disability were addressed by governments, businesses and other stakeholders.

Importantly, where there was high uncertainty in researchers' assumptions, they adopted conservative assumptions to avoid overstating the cost.[8]

The researchers estimate that the cost of violence, abuse neglect and exploitation of people with disability is **at least $46 billion in 2021-22.**[9]

Of that amount, **$27.7 billion relates to issues of systemic failures and neglect**.[10] This includes costs such as:

- The higher rate of avoidable deaths and preventable hospitalisations compared to other Australians (a rate that is even higher among people with an intellectual disability compared with other people with disability)[11]
- The costs of living in inaccessible housing and lower employment rates resulting from discrimination and neglect.

The researchers estimate **an additional cost of $28.8 billion relating to gaps in outcomes**,[12] including the over-representation of people with disability in poor outcomes such as ill-health, low educational attainment and unemployment, and under-representation in access to financial and social opportunities.

As part of their modelling, researchers estimated the annual economic cost of violence, abuse, neglect and exploitation by measuring the rate of interpersonal maltreatment among demographic group, disability type, and level of functional impairment. The findings showed the cost per person is high for people with an intellectual, learning and developmental disability.[13] This reflects the high rates of interpersonal maltreatment and higher costs of systemic failures (such as those listed on page 5 of this submission) experienced by our community.

A phased transition to an inclusive Australia

Clearly, there is both a moral and economic imperative to achieving a society in which all people can live an inclusive life, free from violence, abuse, neglect, and exploitation. At a macro level, there is much to be done to address the challenges and opportunities put forward in the 222 recommendations of the Disability Royal Commission.

It will take time to leverage the legislative instruments, policy, service provision and the overarching ways we structure and organise our communities to enable a truly inclusive society. Research commissioned by the Disability Royal Commission described the magnitude of the task:

"We need to address issues of stigma, discrimination and unfounded and low expectations that arise from biases and fear. We need to address structural inequalities, including access to housing, education, employment, the means of economic participation and political participation".[14]

Large-scale, systemic change is sorely needed. However, we strongly agree with the Commissioners that in order to achieve the long-term aspirations set out in their recommendations, **the reforms needed in the short-term must be gradual and thoughtfully phased.**

This phased transition must centre around three key elements, which must be sustainably resourced by government:

Designing a phased approach to reforms: three key elements

1. **Equitable collaboration with people with an intellectual disability and their families through paid employment opportunities to lead and shape policy change:**

   We know that when included early, equitably and meaningfully in systemic advocacy, people with an intellectual disability and families make highly valuable contributions to shaping policy that is fit-for-purpose and doesn't have unintended consequences.

2. **Partnerships with trusted advocacy organisations with specialist expertise in representing the rights of people with an intellectual disability:**

   This includes organisations like Inclusion Australia and our members, who have significant experience and expertise in building trusting relationships in which people—who have often experienced violence, abuse, neglect or exploitation—feel safe and supported to access information resources, share their experiences, build their skills in systemic advocacy and participate meaningfully in government processes.

3. **Prioritisation of people who experience the greatest barriers to inclusion, and who it is likely will experience the greatest impact because of reform.**

   The Disability Royal Commission showed that people with an intellectual disability experience some of the most frequent and severe human rights abuses, and face some of the biggest barriers to an inclusive life. The design and implementation of government reforms must be commensurate to the level of impact they will have for this cohort. At every step of the way, comprehensive risk assessment and mitigation strategies must be implemented to avoid the unintended consequence of leaving anyone worse off because of reforms.

As the example below demonstrates, a phased approach is also a priority of the Disability Royal Commission's Final Report.

Example of a phased approach to reforms

A key recommendation of the Disability Royal Commission surrounds the issue of eliminating subminimum wages.

The Disability Royal Commission commissioned Taylor Fry and the Centre for International Economics to model and cost recommendations for two options for raising and phasing out subminimum wages:

1. A half minimum wage option (a smaller-scale, piecemeal approach to increase wages slowly)
2. A full minimum wage option (a larger-scale, rapid approach to eliminate subminimum wages)

While option 2 would achieve the immediate goal of ensuring no person is paid less than the minimum wage for their labour, Commissioners took very seriously the fact that this option would have a range of unintended consequences which would impact some people with disability more than others.

Among the most significant of those consequences was a high level of job losses.

These job losses would **particularly affect people with the highest support needs, who at the same time experience the most barriers to open employment**.

Job losses in such circumstances would leave those people financially worse off, having to rely on income support payments like the Disability Support Pension alone. It would also have deeply negative consequences for a person's sense of self, purpose, and social connection.

As such, Commissioners agreed that "**we must take steps in the direction of achieving the long-term objective of a minimum wage for all, but this should not be done in a way that would make it likely that many people with disability will be materially worse off by reason of the reforms.**"

We believe the principle of the Commissioners' argument in the example above—that **reforms should not be implemented in ways that would make it likely that many people with an intellectual disability would be worse off by reason of those reforms**—must guide every step of the government's response to the Disability Royal Commission. It must also prioritise people with the highest support needs, who at the same time face the biggest barriers to an inclusive life.

An additional element that forms the rationale for this approach concerns the notion of ending segregation.

Much of the focus in the days and weeks following the release of the Disability Royal Commission's Final Report was on recommendations which aim to phase out segregated settings, including special schools, ADEs and group homes.

The differing perspectives of the Commissioners surrounding the issues and definitions of segregation reflects the differing perspectives among Australians with disability themselves. As Volume 7 of the Final Report notes, the Disability Royal Commission heard reports of "very different experiences in environments that appear to be similar",[15] such as in special schools, ADEs or group homes.

Commissioners Bennett, Galbally and McEwin describe the following definition of segregation:

Segregation describes the deliberate and systemic separation of people with disability to live, learn, work or socialise in environments apart from people without disability. Segregation is a form of exclusion that limits or denies access to places where the community live, work, socialise or learn because of the person's disability. It also denies full participation on an equal basis in these domains. It is enforced through laws, policies, structures, systems and social norms.[16]

Importantly, the Commissioners agree on what segregation is not:

Segregation does not occur in spaces where people with disability choose to come together voluntarily for a common purpose. Whether to share culture and values, seek solidarity, provide peer-to-peer support to others who relate to their needs and struggles, or share social justice goals, these are the same choices available to people without disability and they do not limit access to, and full participation in, society on an equal basis with others.[17]

We agree with the nuance expressed by these Commissioners and consider segregation to mean settings (physical settings or policy settings that give rise to certain practices) in which there are different laws, rules and practice for a group of people because of a particular characteristic (in this case, intellectual disability). Such settings, whether intentionally or not, incentivise and perpetuate separation from the wider community and significantly restrict choice and control. We discuss these issues in greater detail on page 17.

As evidence from the Disability Royal Commission (cited on page 9 of this submission) showed, people with an intellectual disability are more likely to experience life in such settings, especially special schools, ADEs and group homes. This reflects outcomes of what we call the 'polished pathway'.

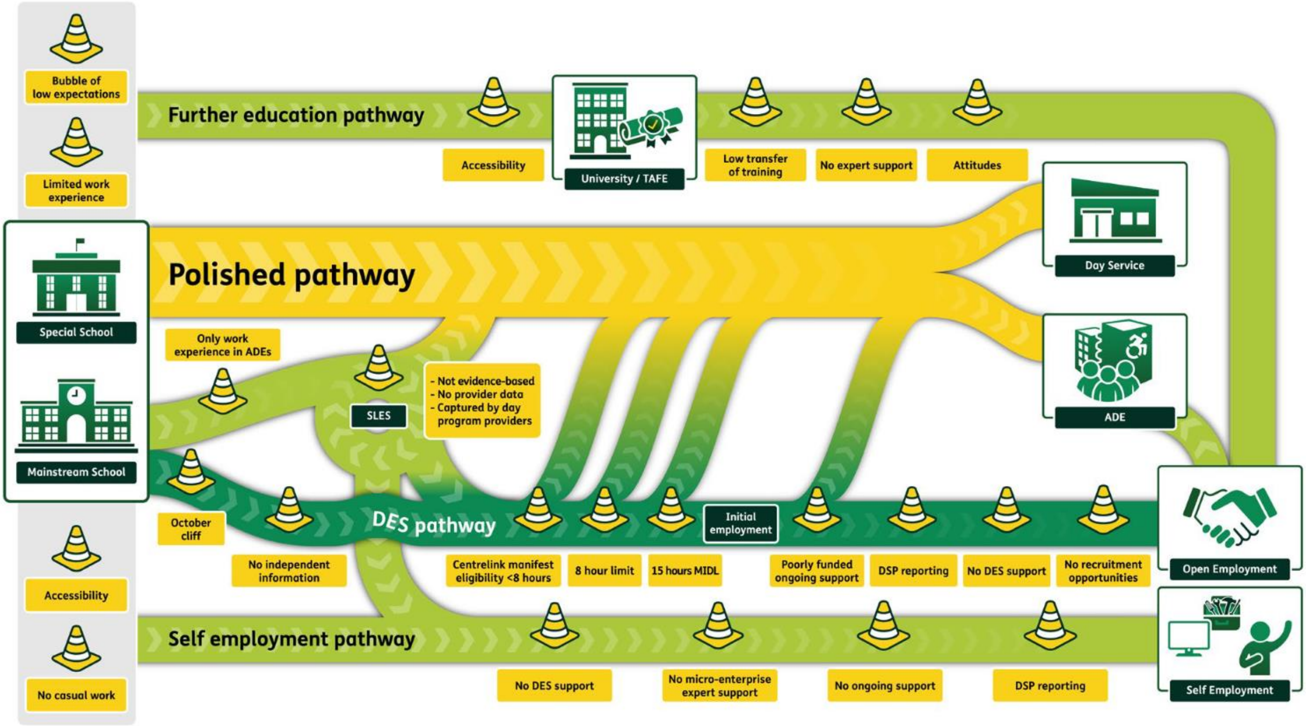
The Polished Pathway

The polished pathway describes an incremental journey from childhood to adulthood that many people with an intellectual disability experience. It usually begins with small decisions in childhood, where families are trying to navigate complex, overwhelming systems to make what are perceived as safe parental choices for their child.

An example of this may be being told in early childhood intervention that "your child will never cope in mainstream school". So, families 'choose' special school.

Over the next few years, supports like specialist transport—which wouldn't be offered at the local, mainstream school—make it easier to stay.

Later, when a young person becomes eligible for the Disability Support Pension, the only employment information a family is given is about Australian Disability Enterprises (ADEs). Families usually have no support to find information about what other choices and supports might exist.



Source: Inclusion Australia, 2022.

These are examples of ‘polish on the pathway’, which lead people with an intellectual disability on a separate path from their peers without disability: to poorly paid work, congregated housing, and a lack of choice and control.

The polished pathway is shaped by low community expectations and supported by interlinking systems.

The connections between these systems, from early childhood intervention to Centrelink, the NDIS and Disability Employment Services, and especially from school to work, are so smooth that families don’t tend to see they are heading towards a predetermined destination.

And while people with an intellectual disability are made invisible to their peers—who experience life on an utterly different trajectory—those peers (who grow up to be potential colleagues, employers, and decision makers) forever lose the opportunity to gain experience about the strengths and similarities of their peers with an intellectual disability, and vice-versa.

While the polished pathway remains the dominant experience for people with an intellectual disability and their families, this cohort will continue to disproportionately experience the poorer outcomes and inequities listed above.

They will continue to experience, as the Disability Royal Commission demonstrated, the most severe human rights breaches.

It is only by strengthening and building genuine choice and inclusive options for people with an intellectual disability and their families that we can begin to remove the 'polish on the pathway' and create an inclusive Australia.

Developing government's response to the Commissioner's recommended transition away from segregation

All Commissioners agreed on very important aspects of the meaning of segregation, including that no-one should be forced to live, learn or work in settings designed exclusively or primarily for people with disability. Importantly, they agreed that:

> *To the extent mainstream services or programs effectively force people with disability into separate settings such as group homes, non-mainstream schools or ADEs, reforms should be introduced to ensure mainstream services and programs meet the needs of and provide the supports needed by people with disability.*[18]

As a result of the range of different lived experiences and interpretations surrounding the term 'segregation', the Final Report contains several recommendations (and derivatives of recommendations based on differing perspectives among the five Commissioners) that aim to phase out certain settings they define as being segregated, according to the definitions cited earlier.

These long-term reforms are needed.

However, they can only be achieved in fair, equitable and sustainable ways and avoid unintended consequences through a gradual, phased transition that is guided by the three elements set out on page 11 of this submission.

We believe there are a range of smaller scale, yet impactful and necessary recommendations made by the Disability Royal Commission that must be acted on by government as a matter of priority.

We set out these priority recommendations in the following section. There, we discuss how and why we believe the government must respond to them to ensure reforms are fit for purpose, do not have unintended consequences that leave some people with disability worse off, and result in the best possible outcomes for all Australians to live an inclusive life.

Inclusive Employment

Select key recommendations from the Disability Royal Commission for government priority

Disability Employment Services

We strongly believe—as we have argued in several previous submissions to DSS[19]—that people with an intellectual disability need to be prioritised in the design of a new DES model. In part, this means providing paid opportunities for people with an intellectual disability to inform and lead change.

In its current form, DES is failing people with an intellectual disability. Fewer than 10,000 people (3.1% of the DES caseload) supported by DES are people with an intellectual disability,[20] yet the level of need for tailored support to enter the mainstream workforce is highest among this cohort: people with an intellectual disability are among the most marginalised when it comes to employment, with only 39% of people with an intellectual disability in the labour force (including people looking for work).[21]

As such, the following recommendations put forward by the Disability Royal Commission must be acted on by government as a matter of priority.

Recommendation 7.16 Priorities for inclusion in the new Disability Employment Services model

The Australian Government Department of Social Services should ensure that the design of the new DES model:

- Is developed using inclusive design principles, and co-designed by people with disability who are employed as paid members of the design team
- Adopts customised employment models as a core component of service provision
- Ensures funding arrangements facilitate flexible employment supports, such as customised employment, and support the progress of Disability
- Employment Services participants in achieving employment goals and long-term employment outcomes
- Considers options to remove the requirement for a person to have a minimum future work capacity of eight hours a week in order to access the Disability Employment Services program, to facilitate access for all people with disability to the new model

We support this recommendation in full and emphasise the need **to remove the requirement for a person to have a minimum future work capacity of eight hours** in order to access Disability Employment Services (DES).

Currently, people with an intellectual disability who are assessed as being able to work less than eight hours per week, or more than eight hours per week without support, are not automatically offered DES Support. While they can technically self-refer, this very rarely happens in practice (and there is no accessible information on how to do this)—with the effective result being a denial of access to DES support. This needs to change.

Getting in the door of DES needs to be the easiest part of starting to look for a job.

All people with an intellectual disability should be eligible for DES support as soon as they are 15 years of age, and for their entire working lives.

We recommend that as part of the government's planning in relation to Recommendation 7.16 of the Disability Royal Commission, the following must also be implemented.

Additional reforms to implement as part of Recommendation 7.16:

- Ensure that everyone who wants employment support is eligible and referred for DES services, no matter how many hours they want to work.
- Ensure all people with an intellectual disability who use the NDIS should be automatically referred to DES if they want to work.
- Replace Job Capacity Assessments with a strengths-based evaluation that focuses on what the person wants to do and the supports they need to do that.
- Fund specific long term, DES support for older people with an intellectual disability who have either never worked in mainstream employment, have had long periods out of the workforce, or who want to explore other work options after working in an ADE.

Recommendation 7.17 Develop education and training resources for Disability Employment Services staff

The Australian Government Department of Social Services should develop a suite of accessible education and training resources for providers of Disability Employment Services to upskill their staff. Resources should be co-designed by people with disability and involve consultation with advocates, employers and Disability Employment Services providers. Resources should address the gaps we have identified, including in:

- Disability awareness
- Cultural competence
- Human rights
- Customised employment
- Employer engagement
- Disabilities Employment Services guidelines and procedures.

We support this recommendation in full and emphasise the need for resources to train DES staff about the needs of people with an intellectual disability specifically, and what works for this cohort in getting and keeping a job.

This reflects our overarching argument that the people with the highest support needs must be centred throughout the government's reform agenda. As noted above—and emphasised in Volume 7, Part B of the Disability Royal Commission's Final Report—people with an intellectual disability, especially those with high support needs, face the biggest barriers to open employment.

As such, up-skilling DES providers in evidence-based practice to support people with an intellectual disability needs to be prioritised.

The evidence about what works to support people with an intellectual disability at work is clear both nationally and internationally, but is not reflected in the current DES system. This evidence says that people with an intellectual disability need:

- The presumption of employability among parents, educators, employment services, the business sector, government and the wider community
- A high level of job customisation to suit the needs and interests of the individual and the employer, including job carving, job sharing and job creation
- Proactively seeking job opportunities and connecting individual job-seekers to employers (instead of waiting for job vacancies to be advertised), and that this begins as early as possible, with an emphasis on the role of schools to make those connections
- On-the-job training or on-site training mixed with work experience
- Time unlimited support in the workplace to continue to acquire work-related skills and capacity to independently access and maintain employment
- A strong role for employment brokers or vocational specialists to work with disability support services, health services (including mental health services), employment services, training organisations, schools, employers, families and jobseekers.[22]

Recommendation 7.18 Establish specific and disaggregated targets for disability employment in the public sector

The Australian Government and state and territory governments should adopt specific and disaggregated targets to increase the proportion in the public sector of:

- Employees with disability at entry and graduate levels
- Employees with disability at executive levels
- Employees with cognitive disability.

Public sector targets should be supported by:

- Clear employment pathways into the relevant public services for each target cohort
- Measures and programs to support the recruitment and progression of each target cohort
- Provision of appropriate supports.

The Australian Public Service Commission and state and territory public service commissions should ensure these targets contribute to their existing overall employment targets for people with disability.

Recommendation 7.19 Establish specific disability employment targets for new public service hires in agencies and departments

The Australian Government and state and territory government departments and agencies should be required to set a target to ensure that a proportion of new public service hires to their respective workforce are people with disability.

The target should be at least 7 per cent by 2025.

The target should increase to at least 9 per cent by 2030.

We strongly agree with these recommendations, and that all levels of government need to play an active role in opening employment to people with an intellectual disability and providing and modelling the right support.

Currently, the Australian Public Service Disability Employment Strategy sets a target of 7% for people with disability but makes no mention of people with an intellectual disability, nor sets specific targets.

The NDIA, DSS and the NDIS Commission are well placed to model and grow employment for people with an intellectual disability. We firmly believe that these agencies must set specific and ambitious targets for the employment of people with an intellectual disability. This will demonstrate leadership and a model of good practice for the rest of government and should be implemented as a matter of priority.

In our submission to the Disability Royal Commission, we also made the following recommendations around setting targets for employment, which we argue should be implemented in conjunction with the above Disability Royal Commission recommendations:

Additional reforms to implement as part of Recommendation 7.18 and 7.19:

- Set targets at each level of government for employment of people with an intellectual disability in their public sector disability employment strategies
- Ensure all government departments and agencies—such as the NDIS, the NDIS Quality and Safeguards Commission and the Department of Social Services at the federal level—that directly work with people with disability set higher targets for employment of people with disability, including specific targets for people with an intellectual disability
- Provide funding to local government, starting in regional areas, to facilitate the employment of people with an intellectual disability
- Ensure DES works with local government and NDIS providers in regional areas to facilitate employment, particularly to meet the new employment targets.

Our vision for a DES system that works for people with intellectual disability and their families

A DES system that supports people with intellectual disability into open and self-employment, and sustains that work, looks very different to the current system. A system that works for people with an intellectual disability is one where:

- People with intellectual disability and their families find it easy to get accessible information about and to access open and self-employment.
- The forthcoming **Disability Employment Centre of Excellence** provides evidence-based research and best practice material to a network of **specialist DES providers in each state and territory**. In addition, they facilitate a high-level taskforce to harmonise settings across government.
- Specialist DES providers can be accessed from anywhere in the state or territory, and implement the **evidence-based practice** in everything they do. There is widespread expertise, education and training about **what works for people with an intellectual disability,** and this is continually improved through ongoing investment from government in developing research and evidence-based practice.
- Education and training about what works for people with an intellectual disability is delivered by people with an intellectual disability and families, and people are renumerated for doing so.
- Mainstream DES providers get training from the specialist DES and work in their communities to invest the time and expertise so people with intellectual disability can access open and self-employment.
- The **NDIS and DES work together**, alongside other government agencies, such as Centrelink, to ensure that people with intellectual disability do not have barriers to finding and keeping work.
- DES staff are well trained, supported and funded—with sustainable funding mechanisms—to ensure they have the **time and resources needed to support people with intellectual disability.**

Australian Disability Enterprises

Australian Disability Enterprises (ADEs) are currently one of the few places where people with an intellectual disability can get employment. However, within this model workers with disability earn well below the minimum wage and rarely have a choice about where they work or what they do.

ADEs were started as an alternative to institutions for people with an intellectual disability, at a time when expectations and understandings about intellectual disability were very limited. As people with an intellectual disability advocated, these expectations have shifted. Yet in many ways, the structures and systems of ADEs still perpetuate this historical legacy.

We consider that ADEs constitute segregated settings, in that the systems in which they operate give effect to certain policies and practices that only apply to people with an intellectual disability, who are also excluded from accessing other employment options.

When a person with an intellectual disability is employed in an ADE, the system imposes rules on them that don't apply to any other worker in Australia. These include:

- Productivity assessments that set their wages
- Low expectations and widespread negative attitudes about the work they do
- Being legally paid very low wages, as little as 12.5% of the minimum wage.

In addition, supports in employment that should be found in a wide range of settings, are often only found in ADEs for people with an intellectual disability. People with an intellectual disability also often only get group employment supports in their plans, rather than the individualised supports the NDIS promised. This does not apply to other people with disability who get NDIS supports.

For people with an intellectual disability who have employment, most work in ADEs.

More people with an intellectual disability who use NDIS supports, who are aged 25 years and over and are employed, have employment in ADEs (70%), with only 15% having a job in open employment on a full wage, and a further 13% having a job in open employment on a below-minimum wage.[23] Younger people with an intellectual disability who use the NDIS (aged 15-24) are more likely to be in open employment (on both below minimum and ordinary wages) than employed by an ADE.[24]

There is evidence that early placement of young people with an intellectual disability into segregated day programs and employment options reduces their later economic participation.[25]

There is strong evidence that once in segregated employment settings, such as ADEs, few transition into open employment. In 2014, less than 1% of those employed in an ADE transitioned to employment in the mainstream labour market.[26] Similarly, National Disability Services suggests that less than 5% of people with disability transition to open employment from day services or supported employment settings in Australia.[27]

What people with an intellectual disability and families have told us

In late 2022 and early 2023, Inclusion Australia undertook a substantial policy project with people with an intellectual disability and families, exploring barriers and opportunities to inclusive employment. As part of this project, we conducted extensive stakeholder engagement over several months including a project advisory group, interviews, surveys, and individual consultation. Several key themes emerged from the experiences people with an intellectual disability shared about their experiences in ADEs and their ideas about what needs to change. The most common themes were:

- Wages are too low: people with an intellectual disability need to be paid a proper wage
- There are not enough jobs for people with an intellectual disability in open employment
- People need ongoing, individualised support to find and sustain employment
- Employer attitudes and low expectations can be a barrier
- The system is too complex: individuals and families who use Disability Employment Services, NDIS, Centrelink and other governmental agencies are overburdened with the significant administrative workload and inaccessibility of these systems
- People with an intellectual disability want—and have a right—to feel safe at work, and to be included and belong in a meaningful way

This final point is critical for the government to remain cognisant of, especially in relation to calls to end segregation set out in some of the Disability Royal Commission's recommendations.

When people with an intellectual disability express a desire to want to work alongside other people with an intellectual disability, this does not itself constitute segregation or congregation. We have learned through extensive consultation with our community that people with an intellectual disability care deeply about the social connections and friendships they form with other people with an intellectual disability in ADEs—just like many other workers in many other jobs.

While making friends is not the purpose of work, **it is also not the goal of inclusive employment to ensure that people with an intellectual disability only work alongside people without an intellectual disability.** Many people with an intellectual disability do not feel safe in open employment settings, or experience loneliness and isolation.

As we pointed out earlier in this submission, the Commissioners were clear that:

> *Segregation does not occur in spaces where people with disability choose to come together voluntarily for a common purpose. Whether to share culture and values, seek solidarity, provide peer-to-peer support to others who relate to their needs and struggles, or share social justice goals, these are the same choices available to people without disability and they do not limit access to, and full participation in, society on an equal basis with others.*[28]

People with an intellectual disability have a right to feel safe, connected and have a sense of belonging at work—just like any other employee. These elements are, for all people, closely related to job satisfaction and are even associated with increased productivity and fulfilment at work.[29]

As such, any plan to transition away from ADEs must be cognisant of this and take place alongside a measurable increase in the open employment positions available for people with an intellectual disability and supported to remain safe, connected and with a sense of belonging.

Given this background, we strongly believe that the government must prioritise the following recommendations from the Disability Royal Commission in relation to ADEs.

Recommendation 7.29 Embed an 'open employment first' approach in the NDIS Participant Employment Strategy

Following the conclusion of the NDIS Participant Employment Strategy in 2023, the National Disability Insurance Scheme (NDIS) should adopt an 'open employment first' approach in the next iteration of the strategy. The strategy should:

- Ensure the development of employment goals in participants' NDIS plans considers employment in open and integrated employment settings as a first option
- Provide training for Local Area Coordinators, National Disability Insurance Agency planners and support coordinators to build knowledge, resources and capacity to encourage participants to –
    - develop employment goals in open and integrated employment settings as a first option
    - identify appropriate supports available to achieve open employment goals.
- Establish a target to increase the proportion of participants in open and integrated employment settings
- Build the knowledge and capacity of NDIS employment support providers to assist participants to –
    - transition from Australian Disability Enterprises to open and integrated employment settings
    - provide ongoing support in open and integrated employment settings.

Recommendation 7.30 Support the transition to inclusive employment

The Australian Government Department of Social Services should develop a plan to support people with disability working in Australian Disability Enterprises (ADEs) to move to inclusive, open employment options in a range of settings. The plan should incorporate:

- The option for people with disability to continue working in ADEs, with strong and appropriate safeguards, if that is their free and informed choice. Commissioners Bennett, Galbally, Mason and McEwin provide a recommendation to phase out ADEs by 2034 (Recommendation 7.32). They support this element of Recommendation 7.30 until ADEs are phased out
- Action to increase employment opportunities in open and inclusive settings for people with disability (linking with Recommendation 7.29)
- Improved information for people with disability about employment supports, opportunities in other settings, wages and the Disability Support Pension (linking with Recommendation 7.28)
- Active consultation with people with disability, Disability Representative Organisations and Disabled People’s Organisations Australia, and the adoption of inclusive design principles in developing and implementing the plan
- The Australian Government working with industry to support people with disability to access more inclusive, open employment options and to transform their segregated employment services to a more comprehensive service offering
- Improved collaboration between the National Disability Insurance Scheme and DES to ensure different employment services work cohesively to deliver supports for people with intellectual disability and others

We agree with that these recommendations should form the basis of the government’s approach to the transition towards inclusive employment for all people with an intellectual disability.

However, as we have argued throughout this submission, people with the highest support needs must be centred throughout the government’s reform agenda.

We emphasise that people with an intellectual disability—particularly people with high support needs—must be provided with tailored and fully resources support to be able to continue working in ADEs if it is their choice, with the added requirements that:

- People with an intellectual disability and their families or other supporters are provided with accessible information about their employment options, including choices about different employment supports
- ADEs must be resourced to provide people with support and pathways to open employment if they change their mind about working in an ADE and/or gain more skills and experience and want to get a job in open employment

- In relation to the points above, ADEs must have an individualised employment plan for every worker—the development of which must happen in supported, person-centred ways that includes access to Supported decision-making as discussed below
- ADEs must be resourced to undertake comprehensive data collection to quantify the precise number of people looking for open employment, including the extent to which individuals have access to Supported decision-making to make those choices
- This phased approach to the transition away from ADEs must take place alongside a measurable increase in the open employment positions available for people with an intellectual disability. This is critical to ensure that the move away from ADEs does not take place in a silo, leaving people without other options in open employment.

Gaps in the Commissioner's recommendations about ADEs

The Disability Royal Commission's recommendations in relation to the transition away from ADEs do not mention the need for Supported decision-making. We see this as being a major gap.

While there are a range of significant recommendations made in Volume 6 in relation to Supported decision-making (which we discuss elsewhere in this submission), we wish to emphasis to government that Supported decision-making is key to achieving the Commissioners' recommendations about inclusive employment.

It is well known that people with an intellectual disability have higher decision-making support needs than other people with disability. Yet this is generally not recognised within the NDIS market (and nor in mainstream supports) and there are few resources to support people with an intellectual disability to make decisions about employment.

Additional reforms to implement as part of Recommendation 7.29 and 7.30:

- Ensure access to Supported decision-making—including a significant investment in independent, accessible information about employment and support options—is resourced and implemented as part of these reforms.
- Partner with disability advocacy organisations—especially those with specialist expertise in supporting people with an intellectual disability and developing Supported decision-making resources—to support the transition to inclusive employment.
- Ensure ADEs are resourced to provide people with support and pathways to open employment if they change their mind about working in an ADE and/or gain more skills and experience and want to get a job in open employment.
- Enable ADEs to develop individualised employment plan for every worker and to undertake comprehensive data collection to quantify the number of people looking for open employment, including the extent to which individuals have access to Supported decision-making to make those choices.

Wages

Recommendation 7.31 Raise subminimum wages

a. The Australian Government should introduce a scheme to ensure that employees with disability are paid at least half the minimum wage. The scheme should include:

Revision of the productivity-based wages calculation to accommodate the move to a new minimum amount of 50 per cent of the current minimum wage

A provision for the Australian Government to subsidise employers for the difference between the wages payable under the relevant award or enterprise agreement and the new minimum wage until 2034.

b. A review of the scheme should be undertaken by the Disability Reform Ministerial Council after five years of operation.

c. The Australian Government should use the results of the review to develop a model and pathway to lift minimum wages payable to employees with disability to 100 per cent of the minimum wage by 2034.

We support this recommendation in full.

We have heard time and again from people with an intellectual disability and their families that the most important issue they want fixed about employment is to be earning more for their work.

People with an intellectual disability can legally be paid a percentage of ordinary wages through the Supported Employment Services (SES) Award and the Supported Wage System (SWS). Subminimum wages[30] can be paid to certain people with disability under this current framework. The issue of subminimum wages was a key theme addressed by the Disability Royal Commission in its Final Report.

The payment of subminimum wages is a feature of Australian Disability Enterprises (ADEs). Subminimum wages can also be paid in open employment settings if they are permitted under the respective award or enterprise agreement.

In its Final Report, the Disability Royal Commission described the impact of subminimum wages on people who work in ADEs, who:

"… Experience unfair treatment compared to people without disability because of the very low wages they can be paid. The unfairness is not limited to the difference in monetary value. Low wages may impact one's financial security, quality of daily life and enjoyment of their human rights. The potential impacts of low wages on a person's wellbeing and self-worth are relevant to whether that person is being exploited … The discussion about wage rates for people with disability working in ADEs is sometimes framed as a choice between ADEs paying full minimum wages to people with disability or ceasing to operate. In light of the evidence, ***it is necessary to move away from this binary position, and to examine the potential for transition to full wages and any intermediary***

***steps that can be taken to improve the immediate situation** to provide for dignity and respect of people with disability earning very low wages."*

Taylor Fry and the Centre for International Economics were commissioned by the Disability Royal Commission to model and cost two options for raising subminimum wages:[31]

1. Raise all wages of people with disability to at least half the minimum wage (the 'Half Minimum Wage Option')
2. Raise all wages of people with disability to full minimum wage (the 'Full Minimum Wage Option')

The Disability Royal Commission has recommended the Half Minimum Wage Option be adopted by the Commonwealth Government as a first step, with the proviso that "raising wages to 50 per cent of the minimum wage is not a perfect solution and should only be an interim measure" towards the longer-term objective of full minimum wages by 2034 for all people with disability currently receiving subminimum wages.

As mentioned earlier in this submission, the Commissioners raised concerns about the significant job losses identified by Taylor Fry's modelling as a potential unintended outcome of the Full Minimum Wage Option. Those job losses would especially impact people with the highest support needs, who at the same time are the most marginalised from open employment.

As such, the Disability Royal Commission's Final Report sets out a three-stage approach based on the Half Minimum Wage Option modelled by Taylor Fry. This modelling assumes a 10-year implementation pathway, which we believe the government must act on as a matter of priority.

Disability Support Pension

Among people with disability, people with an intellectual disability are among the least likely to receive an income from a wage or salary through employment: 72% of people with an intellectual disability's main source of income comes from a government pension or allowance.

The most common government payment for people with an intellectual disability is the DSP.[32] The AIHW reports that 71% of people with an intellectual disability receive the DSP. Many people with an intellectual disability rely on the DSP for their whole adult lives.

The Disability Royal Commission makes an important recommendation in relation to the DSP, which we believe must be implemented urgently by government:

Recommendation 7.28 Improve information about wages and the Disability Support Pension

The Australian Government should fund Disability Representative Organisations to deliver an information campaign for employees with disability in Australian Disability

Enterprises. This campaign should provide information about:

- Open employment, including wage conditions
- How receipt of the Disability Support Pension (DSP) interacts with a person's wages, including:
    - Assistance with financial literacy materials
    - Supports for individuals to calculate how changes to their DSP or wages impact their overall income and financial situation
- Options for a person to suspend their DSP if they are earning above the threshold
- Who to contact to ask questions or obtain further information.

This information should be available in a range of accessible formats.

However, there are major gaps in the Disability Royal Commission's recommendations in relation to income support.

We firmly believe that people with an intellectual disability should be able to reap the financial benefits of working in open employment. In its current form, the DSP system disincentivises people with an intellectual disability to earn more from their wages or increase their hours at work because of the thresholds at which the DSP begins to decrease as a result of earning more, and the taper rate itself. We know that many people with an intellectual disability fear losing their DSP in entirety if they choose to work or earn more.

For people with disability who do not meet the manifest eligibility rules, such as people with an intellectual disability with an IQ of more than 70 and less than 85, they must not be able to work more than 15 hours per week in the next two years.[33] For people with manifest eligibility, there are no minimum or maximum work requirements.

People with Disability Australia (PWDA), with the Anti-Poverty Centre, also made a submission and gave evidence at the Disability Royal Commission. PWDA said:

> *The DSP can only be adequate when it does at least three things: firstly, provide guaranteed lifelong income to keep every person with disability out of poverty; secondly, act as a gateway to greater supports that allow us to self-determine how we live our lives to the greatest extent possible; and thirdly, it is not treated as an unemployment payment and must be a well-designed payment that will provide us with what we need to find suitable paid work on our own terms.*

In 2021, the Senate Community Affairs Committee held an inquiry into the DSP. The Final Report was issued in February 2022 and made the following recommendations, which we believe must be implemented by government as a matter of priority, alongside Recommendation 7.28 cited above:

Additional reforms to implement as part of Recommendation 7.28

- Reform the income test for recipients of the DSP to better support people facing structural barriers to participating in the workforce, and to better recognise the fluctuating nature of a person's ability to participate in paid employment.
- Raise the income thresholds at which the DSP payment is reduced and lower the taper rate by which it is reduced once this threshold is reached.

Inclusive housing

Select key recommendations from the Disability Royal Commission for government priority

The Disability Royal Commission heard evidence across a range of public hearings about the violence, abuse, neglect and exploitation that people with disability can experience in some group homes.

As we pointed out earlier in this submission, adults with an intellectual disability are likely to be living in a group home. Volume 7 of the Final Report summarised what the Disability Royal Commission heard about the harms experienced within some group homes:

> *People with disability have experience violence and sexual abuse from staff and co-residents in the form of physical violence, sexual assaults, sexual exploitation, psychological or emotional abuse, and harassment. We also heard about the use of coercive control and financial exploitation by staff members and the use of chemical and physical restraints. The evidence reveals examples of neglect, such as failures to protect peoples' safety, safeguard their health, maintain proper hygiene, and provide support to learn about relationships, life skills and different options for housing.*[34]

Fully inclusive living is possible for people with an intellectual disability, including people with high and complex support needs. The Disability Royal Commission heard about a number of innovative housing models that are already progressing in Australia.

Investment in and evaluation of these models is in its early stages, and the Disability Royal Commission has strongly recommended further investment in their development to urgently expand the supply of sustainable housing options, with an emphasis on the significant unmet need among people with complex needs.[35]

There is strong evidence to suggest that investment in alternative and inclusive housing models will:

- Provide greater choice and control for people to live an ordinary life and improve social and economic participation
- Reduce experiences of violence, abuse, neglect, and exploitation toward people with disability
- Strengthen communities and promoting inclusion
- Enabling administratively more simple home and living supports, which will enable providers to be viable and their workforce engaged and capable of delivering high quality care and support
- A future state for home and living supports that helps to ensure the sustainability of the NDIS.[36]

As *first steps* towards the long-term recommendations made by the Disability Royal Commission, including the phasing out of group homes within 15 years, we strongly recommend the government implement the following Disability Royal Commission recommendations as a matter of priority:

Recommendation 7.41 Group home reform

The NDIS Quality and Safeguards Commission should prioritise the implementation of the Own Motion Inquiry into Aspects of Supported Accommodation – Action Plan (the Action Plan) and expand actions to include:

a. a specific review of mechanisms to transition away from allowing the same provider to provide Supported Independent Living (SIL) and Specialist Disability Accommodation (SDA) services, with interim arrangements to strengthen oversight to address and monitor conflicts of interest (under Action 8)

b. strengthening how disability providers implement models of practice, such as Active Supports, to ensure that people with disability living in group homes are actively supported to have opportunities for greater social interaction and community participation and inclusion (under Action 2)

c. developing an implementation plan for the Action Plan, with –
    - explicit timeframes for delivery
    - annual reporting on progress and outcomes to the Disability Reform Ministerial Council.

In this recommendation, we highlight point a. and emphasis the need to separate SIL and SDA supports, and this this be urgently implemented by government.

To reduce conflict of interest and undue influence, the NDIA must ensure that formal decision support and support coordination is provided *independent of service provision*.

It is highly inappropriate for service providers of accommodation and home supports to support their customers to make decisions about their living situation. This issue has already been well discussed in submissions and reports on Support Coordination, including the Tune Review[37] and the Own Motion Inquiry into Aspects of Supported Accommodation in the NDIS.

Our position is that independent decision-making support is best placed within independent advocacy organisations, Disability Representative Organisations (DROs), peer support organisations, capacity building organisations and disability specific organisations that are independent of service provision.

This is crucial to reduce conflict of interest or undue influence, and to harness the Supported decision-making skills and capacity already present in these agencies. Independent advocates and DRO staff have been supporting people with disability to make their own decisions for decades, including people with complex communication support needs, whose decision-making support needs are usually higher.

Recommendation 7.42 Improve access to alternative housing options

The National Disability Insurance Agency (NDIA) should work with the Australian Government, and state and territory governments, to expand alternative housing options and support for people with disability to access and transition to these options through a proactive market enablement strategy. This should include:

a. an increase in innovative housing options, such as by –
   - expanding the NDIA Home and Living Demonstration Projects with additional rounds from 2024. These rounds should –
     - focus on exploring diverse market mechanisms for sustainable housing models
     - include ongoing extensive and independent evaluation and dissemination of emerging best practice to help bring new models to scale
   - establishing a policy unit to co-design, guide and influence the development and implementation of more contemporary accommodation models
   - conducting comprehensive market research to assess market demand and understand National Disability Insurance Scheme (NDIS) participants' housing preferences to inform state and local governments, housing authorities and developers, and drive innovation.

b. reform of NDIS participant funding models, including Supported Independent Living, Specialist Disability Accommodation and Individualised Living Options to provide greater flexibility. In particular, this flexibility should ensure that administrative and pricing mechanisms do not favour group home living over other models of inclusive housing.

c. development of clear and supportive transition pathways that provide access to advice, advocacy and support for people with disability to understand and explore their housing options, make decisions about transitioning to the housing of their choice, and receive support for that transition. This should include –
   - an individualised assessment of a person's housing needs and preferences, with the option for this to be regularly updated
   - an update of a person's NDIS plan to include specific support, including capacity building to support the decision to transition to more independent living
   - where a person is interested in changing housing, the development of an individual transition plan that identifies current available and emerging alternative housing options, beyond the offerings of their current provider
   - access to independent advocacy and an independent support coordinator to provide support for and facilitate the transition.

Recommendation 7.42 Improve access to alternative housing options

(Continued)

d. prioritisation of the implementation of the NDIA Home and Living Framework, including –

- establishing explicit timeframes for its implementation that recognise the urgency of these reforms, in relation to realising the rights of people with disability under the Convention on the Rights of Persons with Disabilities
- continuing work with the disability community to identify key outcomes and measures, and developing a comprehensive monitoring and evaluation plan to measure and report on progress
- ensuring the chosen approaches address the key elements set out above in this recommendation, including –
    - providing a dedicated pathway for participants with a current or anticipated high need for home and living supports
    - ensuring participants taking this pathway have appropriate and timely support to explore and design individualised home and living solutions that work for them

As part of the government's consideration of the Disability Royal Commission's recommendations regarding group home reform—and as first steps to support the success of those reforms—we strongly recommend investing in:

- Ongoing extensive and independent evaluation and dissemination of emerging best practice in home and living supports. This is referenced in Recommendation 7.42, point a.
- Independent, accessible information resources—especially Supported decision-making—which should include an investment in specialist disability advocacy organisations to work with people with an intellectual disability to develop and disseminate these resources.

These are explained below.

Independent evaluation and analysis of home and living supports

One rationale for the group home model is known as 'economies of scale'. This means it is cheaper for the government or a service provider to provide specialised support (which many people with an intellectual disability require) to five or six residents, requiring one or two staff members at a time, rather than provide one-to-one support for residents living on their own.

On the one hand, it is true that when production becomes efficient, cost benefits are reaped.

However, we believe that there is mounting evidence—much of it gleaned through the Disability Royal Commission itself, and particularly its robust research program—that challenges this conventional economic wisdom in relation to the rationale for shared home and living supports.

This is because of what we now know—which is not exhaustive—about the human and financial cost associated with the systemic and interpersonal violence, abuse, neglect, and exploitation of people with disability.

That economic modelling[38] is discussed at the beginning of this submission, and it demonstrates that **systematically neglecting a portion of the population is very expensive for governments and communities.**

As part of the government's consideration of the Disability Royal Commission's recommendations regarding group home reform, we strongly recommend investing in ongoing extensive and independent evaluation and dissemination of emerging best practice in home and living supports. This is referenced in Recommendation 7.42, point a.

This work should include a cost benefit analysis of shared home and living supports: one that accounts for the human and financial cost of segregated housing options, including what we are now learning about how the following issues are experienced by people with an intellectual disability in those settings, and the costs incurred (to governments, communities and families) as a result of them:

- Experiences of violence, abuse, neglect, and exploitation[39]
- Access to preventative health care measures[40]
- Responding to medical emergencies[41]
- Increased rates of Guardianship orders[42]
- Limited access to decision support and communication support[43]
- Increased use of Behaviour Support Plans[44]
- Increased use of restrictive practices, especially psychotropic medications[45]
- Increased rates of preventable deaths.[46]

An essential part of this work will be to engage directly with people who are receiving shared home and living supports, such as people living in group homes and their families. Partnership with trusted, specialist advocacy organisations, such as Inclusion Australia, is required to ensure that engagement is done meaningfully, safely, and accessibly.

The importance of independent, accessible information and access to Supported decision-making in the context of home and living

Supported decision making and housing options are inextricably linked. A person with an intellectual disability cannot meaningfully choose who they live, where they live or who supports them at home without appropriate decision support.

This is implicit in many of the Disability Royal Commission's recommendations in relation to home and living reforms. However, we wish to emphasis to government that **access to Supported decision-making is non-negotiable when approaching reforms to home and living supports.**

It is well evidenced that people with intellectual disability, who have historically had very limited housing options, tend to have higher decision support needs than other people with disability.

Given that adults with an intellectual disability are likely to reside in group homes and the evidence surrounding the increased likelihood of experiences of violence, abuse, neglect and exploitation in those settings, access to Supported decision-making to build capacity, explore options and ensure appropriate safeguards are in place is crucial.

As reflected in point c of Recommendation 7.42, people should have greater flexibility to explore different housing options. Supported decision-making is foundational to this.

People with an intellectual disability need opportunities to try different housing options. This is not only because of the difficulty many people with an intellectual disability experience in understanding abstract concepts (like the idea of living with one other housemate of their choosing, as opposed to living in a group home), but also, this is an ordinary part of life for many people without disability.

For example, it is common for many young adults without disability to try different house-sharing options as life circumstances fluctuate, preferences evolve, and longer-term decisions are made. People with an intellectual disability have a right to be supported to make similar decisions and to retain choice and control over big life transitions, such as moving out of home.

In addition, we have heard from many people with an intellectual disability that **privacy** is a key consideration when making decisions about different housing options, and something that is very often lacking in shared living arrangements, especially group homes. Privacy should therefore be a key consideration when any further evaluations of emerging housing models are undertaken.

Additional reforms to implement as part of Recommendations 7.41 and 7.42

- Invest in ongoing extensive and independent evaluation and dissemination of emerging best practice in home and living supports
- Invest in a cost benefit analysis of home and living supports.
- Ensure access to Supported decision-making—including a significant investment in independent, accessible information about employment and support options—must be resourced and implemented as part of these reforms.
- Partner with disability advocacy organisations—especially those with specialist expertise in supporting people with an intellectual disability and developing Supported decision-making resources—to support the transition to inclusive employment.
- Ensure SDA and SIL is resourced to provide people with support and pathways to inclusive housing options if they change their mind about their home and living supports at any stage.
- Ensure that specialist advocacy organisations are funded to provide independent decision support and independent accessible information to assist people to explore housing options.

Inclusive education

Select key recommendations from the Disability Royal Commission for government priority

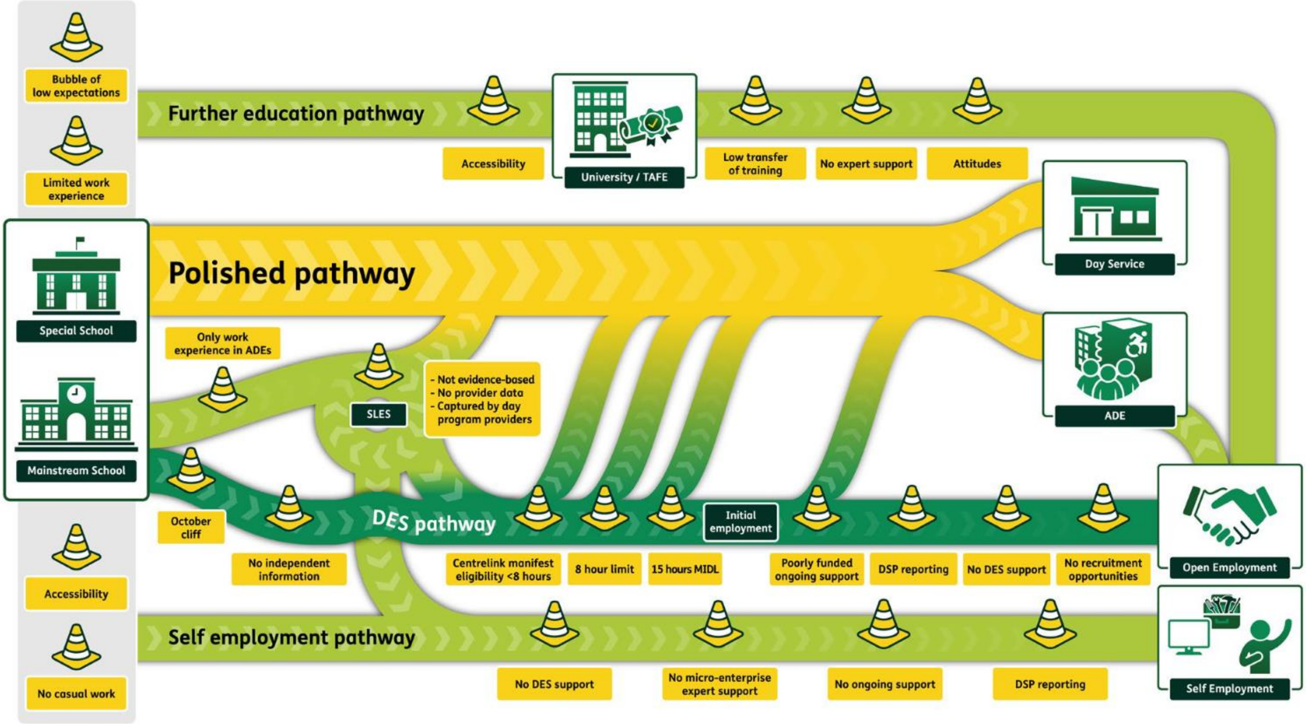
For many families of children with an intellectual disability, decisions about education tend to form the beginnings of what we call the 'polished pathway'.

As discussed in detail at the beginning of this submission, the polished pathway describes an incremental journey from childhood to adulthood that many people with an intellectual disability experience. It usually begins with small decisions in childhood, where families are trying to navigate complex, overwhelming systems to make what are perceived as safe parental choices for their child.

An example of this may be being told in early childhood intervention that "your child will never cope in mainstream school". So, families 'choose' special school.

Over the next few years, supports like specialist transport—which wouldn't be offered at the local, mainstream school—make it easier to stay.

Later, when a young person becomes eligible for the Disability Support Pension, the only employment information a family is given is about Australian Disability Enterprises (ADEs). Families usually have no support to find information about what other choices and supports might exist.



From our perspective, a critical element of the transition towards an inclusive Australia is the removal of the 'polish on the pathway'. We want the barriers to inclusion removed so that all people with an intellectual disability have access to a range of choices, including about education, housing and employment, on an equal basis with others.

We want action to change the polished pathway and ensure students with an intellectual disability and their families have genuine options about education. Our position is that mainstream schools need to have no choice about educating students with an intellectual disability. Students with an intellectual disability and their families need to feel secure to raise issues and solve problems without being pushed into segregated education.

We support Children and Young People with Disability Australia (CYDA) and the Australian Coalition for Inclusive Education roadmap, including the development of a national inclusive education plan (**Recommendation 7.13** of the Disability Royal Commission). We acknowledge CYDA's extensive expertise in this area and support the recommendations they have provided to the Disability Royal Commission across evidence at public hearings and in separate submissions.

We recommend that government implement the following recommendation from the Disability Royal Commission as a matter of priority:

Recommendation 7.1 Provide equal access to mainstream education and enrolment

States and territories should amend education Acts (or the equivalent) to:

- create a legal entitlement for students with disability to enrol in a local mainstream school
- provide that the right to enrolment is subject only to 'unjustifiable hardship' in the sense used in the Disability Discrimination Act 1992 (Cth).

State and territory governments should take the following actions to prevent gatekeeping in mainstream schools:

- maintain a central record of decisions on enrolment refusal or cancellation and provide an annual report to the responsible minister for education on trends and any additional actions required to address barriers
- establish an independent review process to enable a parent or supporter of a child or young person with disability to challenge a refusal to enrol the child or young person in a school.

State and territory educational authorities should disseminate clear, accessible, transparent material for students with disability and their families on their rights, the obligations of schools relating to applications to attend a local school, and review processes.

Further, to reiterate our overarching argument about the need for a phased approach to reform, there are certain smaller scale yet impactful measures that we believe government should take to begin the process of removing the 'polish on the pathway' discussed above.

A key reform from our perspective—which is not articulated in the recommendations of the Disability Royal Commission despite being raised several times during Public hearing 24[47]—is the equitable redistribution of resources for specialist school transport.

Currently, specialist school transport is provided by state and territory governments through in-kind contributions under the NDIS. However, this was intended as a transitional arrangement when the NDIS was first rolled out.

In 2018, the Department of Social Services conducted a National Consultation on a proposed model for specialist school transport being delivered under the NDIS through individual plans. The consultation received "mixed views" on the model. As a result, the Australian Government and state and territory governments agreed that personal care and specialist school transport would be funded through in-kind arrangements until December 2023.

The current school transport system for children and young people with disability has been of significant concern to many DROs for a number of years.[48] For example, we agree with the concerns put forward by Children and Young People with Disability Australia (CYDA) that *"many of the conditions imposed on children with disability who utilise these transport systems violate and deny [their human rights]."*[49]

School transport systems vary across jurisdictions, with each state and territory having a different policy or procedure designed to assist families to apply for NDIS or external service provider supports in schools. In some jurisdictions, such as Victoria, specialist transport programs also include travel training to support independent travel using public transport. However, this is not uniform across states and territories.

As the Disability Royal Commission heard, in most cases, there must be a request from a parent or guardian and approval from the school principal for services from external providers. Some states and territories have developed specific initiatives to support the school interface with the NDIS, but overall, it appears these arrangements are confusing and problematic in terms of implementation.

Our biggest concern regarding the implementation of specialist school transport as an in-kind service through the NDIS is that **the availability of this support is very often linked to particular educational settings,** which limits choice and control and has the unintended consequence of incentivising segregated education.

For example, following Public Hearing 24 of the Disability Royal Commission, Counsel Assisting submitted that specialist school transport is provided for children and young people with disability who attend special/segregated schools, while it appeared that it is not provided for those who attend or want to attend mainstream schools.[50]

We see this as an aspect of the polished pathway.

Having access to specialist school transport increases options and provides support for families. For many families, it is a vital support measure, and for some it is the only transport option to and from school that is available—this is especially the case for people in regional and rural areas.[51]

Having access to specialist school transport also supports women's workplace participation: women represent the majority of primary carers, with recent data showing 54% of families reporting the main person looking after children was a woman, and when asked “who plans/coordinates child activities”, it was usually or always a woman (78% of the time).[52] When families are able to utilise specialist transport for their child or children to get to and from school, it alleviates the time and resources this activity requires from the parent, which is usually the mother.

But when specialist school transport is only offered to children eligible for special schools, it becomes part of the polish on the pathway towards segregation by restricting families’ choices towards one particular education model.

Conversely, if access to specialist school transport was made available to students eligible for special **and** mainstream school, it would result in:

- Increased choice for families about education pathways for their child/ren, including potentially having the option for their child/ren to attend the local school (as opposed to a special school, which is likely to be located further away)
- Equitable allocation of resources across education systems
- Stronger support for women’s workplace participation by increasing options for families.

In its final report, the NDIS Review stated that the current in-kind service arrangements are “inefficient” and have “prevented reform and constrained choice and control for participants and their families”.

The NDIS Review thus puts forward Recommendation 2, Action 2.16—which will require legislative change to the *NDIS Act*:

The Disability Reform Ministerial Council should agree to cease the use of ‘in-kind’ arrangements in the NDIS:

“This is a long running issue that needs to be resolved while balancing other priorities. Governments should consider removing specialist school transport and personal care in schools from the NDIS and returning them to be state and territory government responsibilities. Agreement to a national benchmark for service quality and access for specialist school transport should be a pre-condition.”[1]

Additional reforms to implement as part of Recommendation 7.1

In the long-term, we believe there needs to be an **equitable redistribution of resources** to ensure that students with disability eligible for either a special school or a mainstream school who require specialist school transport can access it.

As a priority in the short-term, we believe that students with disability eligible for either a special school or a mainstream school who require specialist school transport must be provided access to this support as part of their NDIS plans. This should be implemented as a matter of urgency, given the previous agreement from states and territories ended in December 2023.

In the interim, we believe the Commonwealth and state and territory governments need to reach a national agreement about the approach to specialist school transport. As per the NDIS Review recommendation, the approach must include:

- A national benchmark for service quality that is human rights based and designed in partnership with children and young people with disability, their families, special and mainstream schools, and DROs with specialist experience such as CYDA
- A pre-condition that specialist school transport is available and accessible to eligible students who attend either or both special schools and mainstream schools.

Autonomy and access

Select key recommendations from the Disability Royal Commission for government priority

Accessible information

We are pleased to see a range of important evidence and recommendations presented in Volume 6 of the Disability Royal Commission's Final Report in relation to the necessity of accessible information and communications across all life contexts: including the criminal justice system, health care, education, employment, housing, sexuality and relationships, and disability service provision.

It was highlighted by the Disability Royal Commission that access to accessible information and communications is not only a fundamental human right protected by the UNCRPD, but a critical safeguard against violence, abuse, neglect and exploitation. This was particularly demonstrated during the COVID-19 pandemic, which revealed the deficiencies and failings in the accessibility of information and communications for people with disability generally.

The evidence heard during Public hearing 12, 'The experiences of people with disability in the context of the Australian Government's approach to the COVID-19 vaccine rollout', demonstrated that the lack of accessible information and communication put people with an intellectual disability at increased risk of "deteriorating mental health, injury and death."[53]

We vehemently agree with the following recommendation put forward in Volume 6 of the Final Report, and urge the government to implement it as a matter of priority.

While people with complex communication support needs—such as non-speaking people or people who use Augmented and Alternative Communication (AAC)—were not explicitly mentioned in this section of the Final Report, we wish to highlight that this cohort must be considered among the "diversity of people with disability and the many formats and languages that people may require information to be provided in", per Recommendation 6.1 below.

The need for specialist advocacy organisations

It is our firm conviction that governments need specialised systemic advocacy to do this work meaningfully and to help build foundational supports that are genuinely inclusive, meet needs and are fit for purpose.

Systemic advocacy for people with intellectual disability requires expertise that accounts for the need to provide support and develop leadership capacity **with people who have been historically excluded and are still often extremely marginalised.**

As such, supporting and developing capacity with people with an intellectual disability takes time, planning and significant resources from both state and national organisations.

This is not only necessary to meet the support needs of the people we work with and represent, but also to build trusting relationships in which people—who have often experienced significant marginalisation, exclusion, trauma, and even violence, abuse, neglect or exploitation—feel safe and supported to access information resources, share their experiences, build their skills in systemic advocacy and participate meaningfully in government consultation processes.

This work requires an understanding of specialised access and inclusion requirements, and a different way of working to ensure inclusion is genuine. It involves delivering information that is fit for purpose as well as unique analyses to government that corporate consultants cannot offer.

In addition, it is our experience that the voices and experiences of people with an intellectual disability, particularly those with complex needs, can be easily forgotten in cross-disability DRO environments.

As such, DROs with specialist expertise like Inclusion Australia and our members are best and uniquely placed to provide this: it is our organisations who have the expertise to work with people who have been historically excluded and are still often extremely marginalised to create independent and accessible information. We also have:

- Long-established and well-trusted relationships with our communities
- Skills and expertise in developing accessible information and supporting people to access it
- Extensive experience engaging with people with complex needs and with their families[54]
- Supporting the capacity of people with an intellectual disability and their families to exercise genuine and informed choice about their lives.[55]

The provision of independent, accessible information for people with an intellectual disability is a major gap across our society: from government systems to mainstream services and programs to media and technologies. This work enables people with an intellectual disability to take part in community life on an equal basis with others.

Recommendation 6.1 A national plan to promote accessible information and communications

The Australian Government and state and territory governments should develop and agree on an Associated Plan in connection with Australia's Disability Strategy 2021–2031 to improve the accessibility of information and communications for people with disability. The Associated Plan should be co-designed with people with disability and their representative organisations. It should be finalised by the end of 2024. The Associated Plan should:

- consolidate and build on existing initiatives and commitments by governments
- recognise the diversity of people with disability and the many formats and languages that people may require information to be provided in
- consider the roles of various stakeholders, including the Australian Government, state and territory governments, disability service providers, disability representative organisations and organisations representing people from culturally and linguistically diverse backgrounds
- focus, in the first instance, on information and communications about preparing for and responding to emergencies and natural disasters, and public health
- include targeted actions to ensure access to information and communications for people with disability in the criminal justice system; supported accommodation, including group homes; Australian Disability Enterprises; and day programs
- identify and allocate appropriate funding and resources for delivery include mechanisms for review and public reporting of progress made against the Associated Plan.

Guardianship

Evidence gathered by the Disability Royal Commission demonstrates that people with an intellectual disability are overrepresented among people under guardianship and administration orders.[56]

In recent years, there has been a significant increase in reliance on substitute decision-making through Guardianship. This is associated with the rollout of the NDIS a decade ago and has resulted in an increased cost to governments.[57]

For example, Guardianship applications indicating the NDIS as the primary reason for the application have increased significantly in NSW in recent years. In the five years to June 2023, the number of major decisions made by the NSW Public Guardian increased by 164%. Orders authorising the use of restrictive practices in this period increased by 613%.[58]

Similarly, the Disability Royal Commission heard that the NDIS has had a "huge impact" on the Queensland Office of the Public Guardian, with the number of people coming under public guardship increasing and the nature of the work changing.[59] Orders concerning decision-making about support services now make up the highest numbers of order appointing the Public Advocate in WA, which appears directly related to the NDIS. Data collected by the Office of the Public Advocate in Victoria also shows there is an association between the advent of the NDIS and an increase in Guardianship orders.[60]

The Disability Royal Commission has cited several reasons for this increased association between substitute decision-making through Guardianship and the rollout of the NDIS, including:

- The complexity of the NDIS, particularly to fill gaps in advocacy and support coordination services
- The removal of individual case management as the foundation and coordination point for a person's service delivery, which has most notably impacted people who are unable to navigate complex systems without significant support, accessible information, and advocacy.[61]

The NDIS Review's Final Report also cited the following key challenge to enabling participants to access supported decision-making:

A lack of access to tailored information and advice that is proportional to the complexity of the NDIS means many participants struggle to get the information they need to make informed decisions … Capacity building supports for decision-making are fragmented and availability varies across jurisdictions. Many of these supports are not appropriate for people with a high level of support need or for those from diverse groups. This means they are not effective in breaking the cycle of exclusion.[62]

As such, we strongly agree with the recommendations made by the Disability Royal Commission in relation to Guardianship, and believe the following should be implemented as a matter of priority.

We also emphasise that all reforms should be developed in consultation with those who the changes will most impact—people with an intellectual disability, their families and supporters. This means, as we have said, enabling paid opportunities for people with an intellectual disability to shape and lead change to ensure reforms are fit-for-purpose and do not have unintended consequences.

We also note here that we strongly support **Recommendation 6.6**, which we discuss in detail in the following section.

Recommendation 6.5 Objects of guardianship and administration legislation

States and territories should review and reform their guardianship and administration legislation to include a statement of statutory objects which:

- recognises and promotes the rights of people with disability consistent with the Convention on the Rights of Persons with Disabilities (CRPD)
- includes the text of article 12 of the CRPD
- recognises the role of support to enable people who may require support to make, participate in and implement decisions that affect their lives.

Recommendation 6.9 Representatives as a last resort

States and territories should review and reform their guardianship and administration legislation to provide that representation orders should be made only as a last resort and in a way that is least restrictive of a person's rights, autonomy and actions, as practicable in the circumstances. The reforms should include:

a. the repeal of provisions authorising plenary representation orders
b. a requirement that the relevant tribunal should make an order appointing a representative only if satisfied that:
    - the proposed represented person does not have decision-making ability for one or more decisions the order is necessary, taking into account:
        - the will and preferences of the proposed represented person
        - the availability and suitability of less intrusive and restrictive measures, including formal and informal support arrangements, negotiation and mediation
    - the order will promote the person's personal and social wellbeing
c. a provision that the tribunal must take into account, in deciding whether a person (other than a public official) is suitable for appointment as a representative:
    - the will and preferences of the proposed represented person
    - the nature of the relationship between the proposed representative and the proposed represented person
    - whether the proposed representative is likely to act honestly, diligently and in good faith
    - whether the proposed representative has or may have a conflict of interest in relation to any of the decisions referred to in the order

Continued on page 187 of Volume 6:
https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Volume%206%2C%20Enabling%20autonomy%20and%20access.pdf

Supported decision-making

Supported decision-making is a fundamental human right given effect by Article 12 of the UNCRPD, which guarantees every person's right to legal capacity—to make one's own decisions and have those decisions legally recognised—and specifically requires governments to provide people with disability the supports they may need to exercise legal capacity, meaning support for decision-making.

As we have argued in previous submissions,[63] a significant investment in targeted programs which increase the understanding and skills of decision makers and their trusted, informal supporters is paramount to meeting Australia's international human rights obligations.

Supported decision-making is a well-established concept with people with an intellectual disability and their families or other supporters, and this is largely because early supported decision-making initiatives in Canada were focussed on addressing the needs of people with an intellectual disability. Further, people with an intellectual disability were explicitly considered within the ambit of the UNCRPD and some self-advocates with an intellectual disability, as well as intellectual disability advocates more broadly, were heavily involved in its drafting.[64]

As such, engaging directly with people with an intellectual disability and their families or other supporters about how the government can address the Disability Royal Commission's recommendations around Supported decision-making would be extremely beneficial: this group arguably has the most expertise, practice and lived experience of implementing the philosophies and practices of supported decision-making in their lives.

There is an increasing body of evidence that Supported decision-making is itself an important safeguard, but that it also creates other forms of safeguarding by furthering the empowerment and self-determination of people with an intellectual disability in a range of different ways. As research commissioned by the Disability Royal Commission notes, Supported decision-making creates in the decision-maker:

> "Greater exercise of choice and control; support to navigate complex systems; assistance to understand information and explore a broad range of options; increased opportunities to make decisions, and a greater likelihood that decisions would reflect their preferences. By having … one's choice respected, supported decision making was also seen to further confidence, skills in self-advocacy and decision-making, and awareness of individual rights".[65]

Implementing the Disability Royal Commission's recommendations in relation to Supported decision-making is critical, especially because Supported decision-making is essential to enabling many of the other recommendations made by the Disability Royal Commission across a range of areas in its Final Report, not least:

- Inclusive employment
- Inclusive education
- Inclusive housing

- Safeguarding
- The reduction and elimination of restrictive practices
- Guardianship and reducing the need for substitute decision making.

People with communication support needs

People with communication support needs[66] require ongoing capacity building opportunities to develop the different ways that they communicate—through their natural language as well as through the use of alternative and augmentative communication strategies. It is essential that people with complex communication support needs, regardless of their age, receive ongoing capacity building to develop the skills of their paid and informal support people in observing, recognising, understanding and supporting the continued development of the person's expressive communication.

We note that the Disability Royal Commission's recommendations in relation to Supported decision-making do not specifically talk about people with complex communication support needs.

This is a major gap from our perspective. There is mounting evidence that early, ongoing access to communication support is essential to enabling access to Supported decision-making.

Today, there are many adults and older adults with an intellectual disability with communication support needs who did not receive communication support as children or young people. This is because of what is known as the 'candidacy model', which dominated approaches to delivering communication support up until the 1990s and early 2000s. This model was based on a range of 'criteria' it was believe a person needed to fulfil in order to demonstrate 'candidacy' for communication support. Because of these ideas, many children with an intellectual disability were deprived of communication support based on perceptions they were "too something … too 'young', too 'socially withdrawn', too 'intellectual disabled' or 'too linguistically delayed'".[67]

This model has been replaced with the 'participation model', which is a human rights- and strengths-based approach that considers all the research we have demonstrating that the use of early, ongoing communication support has a positive effect on communication abilities, rather than focussing on a largely arbitrary list of criteria to 'qualify' for access to communication support.

This is a big shift, and it has taken place relatively recently. This means that many people with complex communication needs (especially if they are older) may have never had access to communication supports. Access to meaningful, ongoing Supported decision-making is therefore extremely limited.

We agree with the recommendations put forward by the Disability Royal Commission cited below, but strongly recommend to government that an additional investment in supports for those with communication support needs is implemented as a priority. Doing so prioritises the rights of those who face the biggest barriers to Supported decision-making and are more likely to lack other informal safeguards in their lives.

Principle 2—Presumption of decision-making ability of **Recommendation 6.6** below is especially relevant to people with communication support needs, who may be most likely to be denied this basic presumption, including the dignity and rights to support that it enables.

Recommendation 6.6 Supported decision-making principles

a. States and territories which have not already done so should review and reform their guardianship and administration legislation to include the following supported decision-making principles. The legislation should oblige all persons exercising powers, carrying out functions or performing duties under the legislation to have regard to the principles.

Principle 1 – Recognition of the equal right to make decisions
All people have an equal right to make decisions that affect their lives and to have those decisions respected.

Principle 2 – Presumption of decision-making ability
All people must be presumed to be able to make decisions.

Principle 3 – Respect for dignity and dignity of risk
All people must be treated with dignity and respect and supported to take risks to enable them to live their lives the way they choose, including in their social and intimate relationships.

Principle 4 – Recognition of informal supporters and advocates
The role of informal supporters, support networks and advocates who provide support for decision-making should be acknowledged and respected.

Principle 5 – Access to support
People who may require supported decision-making should be provided with equitable access to appropriate support to enable the person, as far as practicable in the circumstances, to:

- make and participate in decisions affecting them
- communicate their will and preferences
- develop their decision-making ability

Principle 6 – Decisions directed by will and preferences
The will and preferences of people who may require supported decision-making must direct decisions that affect their lives.

Principle 7 – Inclusion of safeguards
There must be appropriate and effective safeguards where people may require supported decision-making, including to prevent abuse and undue influence.

Principle 8 – Co-designed processes
People with disability, in particular people with cognitive disability, their supporters and representative organisations, should be involved in the development and delivery of policies and practices on supported decision-making.

Principle 9 – Recognition of diversity
The diverse experiences, identities and needs of people who may require supported decision-making must be actively considered.

Principle 10 – Cultural safety
First Nations people and culturally and linguistically diverse people with disability are entitled to supported decision-making that is culturally safe, sensitive and responsive. This includes recognising the importance of maintaining a person's
cultural and linguistic environment and set of values.

b. The Australian Government and state and territory governments should also take steps to review and reform other laws concerning individual decision-making to give legislative effect to the supported decision-making principles.

Recommendation 6.13 Information and education on supported decision-making

a. States and territories should ensure that, where legislation to this effect is not already in place, the functions of public advocates and public guardians include providing information, education and training on supported decision-making to people requiring supported decision-making and their families, private supporters and representatives (present or prospective), disability service providers, public agencies, the judiciary, tribunal members and legal representatives.

b. States and territories should ensure that, where legislation to this effect is not already in place, public advocates and public guardians are empowered to provide advice and assistance to people who may require decision-making support, including in relation to applications for support and representation orders.

Recommendation 6.14 Systemic advocacy to promote supported decision-making

States and territories should ensure that, where this is not already the case, a statutory body has a function to undertake systemic advocacy to promote supported decision- making. This function should include:

- monitoring, investigating, researching, reporting, making recommendations and advising on any aspect of relevant decision-making legislation
- encouraging the development and improvement of programs, services and facilities that promote the autonomy of people with disability
- supporting organisations that undertake advocacy and education on supported decision-making

Advocacy

Volume 6 of the Disability Royal Commission's Final Report emphasises the critical role of independent advocacy in the lives of people with disability, and especially in the lives of those with the least access to informal supports and safeguards. The Disability Royal Commission also heard evidence about the importance of self-advocacy (and organisations that facilitate peer support and self-advocacy, such as many of our member organisations) in preventing violence, abuse, neglect and exploitation.

Volume 6 discusses evidence heard from a number of people with disability, family members and advocates about the need for systemic advocacy and independent advocacy to complement and promote self-advocacy and family advocacy, especially "when a specific skill set is needed, in closed settings, or where a person with disability lacks formal supports".[68] There is a lot of evidence that this is especially true—yet the most difficult to facilitate—in group homes, or when a person with disability is receiving disability services. Volume 6 states that within these contexts:

> *Opportunities for building informal support networks can be limited or non-existent. We heard this can be because 'staff perceived their purpose for being there as being to look after people' instead of 'to build relationships and participate in the community'. We also heard that staff and management of group homes are in the position to exert control over their residents' lives, creating an environment in which violence and abuse is more likely to occur. The lack of visibility and inclusion means that residents and people outside of the group home can find it very difficult to identify and address violence, abuse, neglect and exploitation. At Public hearing 3, Mr [Kevin] Stone [then CEO of VALID] said 'the only strategy he had ever seen that is capable of making a difference [in group homes] is advocacy'.*[69]

However, across many of its public hearings, the Disability Royal Commission also heard the lack of adequate or consistent funding is a major factor contributing to unmet demand for disability advocacy.

As such, it set out the following recommendation, which we believe must be implemented as a matter of urgency.

Recommendation 6.21 Additional funding for advocacy programs

a. For the financial years 2024–25 and 2025–26, the Australian Government should commit additional funding of:

- $16.6 million per annum for the National Disability Advocacy Program
- $20.3 million per annum for the National Disability Insurance Scheme Appeals Program.

These amounts should be indexed to maintain their value in real terms from year to year.

b. From 1 July 2026, the Australian Government should ensure long-term and stable funding for national disability advocacy programs to meet demand. This should be informed by improved data in line with Recommendation 6.22.

c. From at least 1 July 2026, state and territory governments should ensure long- term and stable funding for disability advocacy programs in their jurisdictions to meet demand. This should be informed by improved data in line with Recommendation 6.22.

Recommendation 6.22 Improved data collection and reporting on met and unmet demand for disability advocacy

The Australian Government and state and territory governments should improve data collection and reporting on met and unmet demand for disability advocacy within their jurisdiction.

At a minimum, this data should:

- be collected and published on an annual basis
- include demographic indicators that show geographic location, First Nations and culturally and linguistically diverse status
- identify, where possible, whether a request for disability advocacy is from or concerns a person with disability who lives in supported accommodation or is in prison or juvenile detention.

This data should be collected and reported on an ongoing basis.

The Australian Government and state and territory governments should include data collection and reporting as a priority work area in the Disability Advocacy Work Plan associated with the 2023–2025 National Disability Advocacy Framework, and progress this as part of future National Disability Advocacy Frameworks or equivalents.

The Australian Government and state and territory governments should work together to ensure consistent definitions and methodologies allowing comparisons across jurisdictions and trends over time.

Publication of the data should commence no later than 1 July 20

We strongly agree with the need for improved data collection to ensure that funding arrangements are fit-for-purpose and address real community need. Additionally, determining the full cost of service delivery must be done in genuine partnership with the disability advocacy sector—including with the recipients of those services, as well as those who *would be* service recipients if access was available to them.

Many disability advocacy and peer support organisations, including Inclusion Australia and our members, are often reliant—in some cases solely—on ILC grants to fund their work. The insecurity and uncertainty of this can have widespread impacts, especially given that once the current three-year ILC funding finishes, there is no guarantee of anything further unless the organisation can formulate a new, innovative project and apply for another grant. This means that important work is often ceased after a grant period, and that time is spent developing new ideas to meet ongoing, established need. It is also dependent on the structure of grants programs, which often changes in line with changing government priorities.

Further, peer support and information services—which are vital to the effective functioning of other service systems—are not currently funded apart from through the ILC and have been neglected since the rollout of the NDIS.

This funding precarity puts enormous strains on the community workforce and takes away organisational capacity which is sorely needed for other aspects of service delivery. It contributes to workforce turnover and burnout and ultimately means that organisations often cannot effectively meet the full service needs of their communities over time.

In addition, developing the capacity of people with an intellectual disability takes time, planning and significant resources from both state and national organisations. This is not only necessary to meet the support needs of the people we work with and represent, but also to build trusting relationships in which people—who have often experienced significant marginalisation, exclusion, trauma and even violence, abuse, neglect or exploitation—feel safe and supported to share their experiences and build their skills in systemic advocacy and participate meaningfully in government consultation processes.

The need for specialist advocacy organisations

As we have mentioned elsewhere in this submission, people with an intellectual disability have few, if any, ways of having their views and interests known by the government other than advocacy. People with an intellectual disability are more likely to interact with multiple public systems, including specialist services, and face unique systemic barriers to an inclusive life—whether in terms of housing, employment, education, justice or health.

It is our firm conviction that governments need specialised systemic advocacy to dismantle those barriers and to help ensure policy and legislative changes are responsive and fit for purpose.

DROs with specialist expertise are central to this. Systemic advocacy for people with intellectual disability requires expertise that accounts for the need to develop leadership capacity and confidence with people who have been historically excluded and are still often extremely marginalised. It requires an understanding of specialised access and inclusion requirements, and a different way of working to ensure inclusion is genuine.

It is our experience that within cross-disability DRO environments, the voices and experiences of people with an intellectual disability, particularly those with complex needs, can be forgotten. People with an intellectual disability and their family members experience unique systemic barriers and possess a high level of expertise through their lived experience. When supported through specialist advocacy organisations to participate in and lead systemic advocacy work, people with an intellectual disability and their families make a strong contribution to public policy and add immense value and efficacy to systemic work.

It is essential that the specific work of DROs is recognised by government in the context of the Disability Royal Commission, and are funded, consulted and partnered with accordingly.

Additional reforms to implement as part of Recommendation 6.21 and 6.22

- Ensure that improved mechanisms for data collection are designed in partnership with independent advocacy organisations, including DROs, and are used to develop funding arrangements that reflect true community need.

Informal supports and natural safeguards

As the Disability Royal Commission describes:

> *Informal supports, also known as informal safeguards or natural safeguards, are the social support networks that provide protection for people with disability by increasing connections, relationships and visibility in the wider community. Informal supports complement formal safeguards and are a preventative measure against the risks of violence, abuse, neglect and exploitation. Enabling and supporting interpersonal relationships is an integral component to building an inclusive Australia.*

Informal supports and natural safeguards include:

- Supported decision-making
- Personal capacity building
- Peer or advocacy support
- Connections to unpaid relationships and community belonging
- The visibility that comes with activity in the wider community.

While informal supports are mentioned variously throughout some of the recommendations put forward the Disability Royal Commission's Final Report—especially in relation to Supported decision-making—**we are concerned that there are no specific recommendations about building informal supports in the lives of people with disability, especially those who experience the greatest barriers to inclusion.**

The Disability Royal Commission published its Overview of responses to the Safeguards and Quality Issues Paper (Issues Paper) in 2021. It details what it heard from individuals, family members, professionals, service providers and advocacy and disability representative organisations about a range of safeguarding issues, including the promotion of natural safeguards.

The Issues Paper clearly demonstrated that better strategies for promoting natural safeguards are needed.

Many respondents explained that unpaid, freely entered relationships are critical protections. Further, the factors that make a 'good life'—connection, relationships, having a job, being part of community—confer the strongest safeguards against abuse. JFA Purple Orange noted that a national conversation around natural safeguards is warranted.[70] Respondents also discussed the importance of mechanisms that help develop friendship networks, build social connections, and access peer support as being some of the most effective safeguarding strategies. Some organisations gave examples of mechanisms like Circles of Support for relationship building outside paid support workers and said that participants should be able to direct their NDIS funds to such activities.[71]

Further, research commissioned by the Disability Royal Commission argued that in exploring the policy and practice directions needed for people with disability to live in an inclusive society that supports their independence and rights to live free from violence, abuse, neglect and exploitation, we need to consider the ways this can and does take place through natural safeguards that arise from community belonging, visibility and feeling valued within one's community, and unpaid social connections. For example, the authors suggested that **there is a need to move beyond simplistic**

notions of physical location or dichotomies of inclusion versus segregation, and towards what is sometimes called ‘psychological inclusion’.

‘Psychological inclusion’ focuses on the extent to which an individual perceives membership in their community, expresses an emotional connection with their neighbours and can fulfil their needs (physical, emotional, spiritual) through community connections. This is potentially one of the least well addressed areas in the literature and is arguably among the most poorly acknowledged in policy and most under-addressed in service and practice. Yet that felt sense of belonging within one’s community is a powerful and robust natural safeguard that prevents violence, abuse, neglect and exploitation. As such, we believe this gap needs to be acknowledged and address by the government through the recommendation below.

Additional reforms to implement as part of the government’s response to Volume 6

- Work with DROs to establish and sustainably fund strategies to build informal supports/natural safeguards in the lives of people with disability, prioritising people with an intellectual disability and those residing in closed settings, who are less likely to have informal supports in their lives.

Health

Select key recommendations from the Disability Royal Commission for government priority

Barriers to health and mental health care

People with an intellectual disability experience a range of barriers to accessing healthcare services—including oral healthcare and mental health services—that are inclusive and meet their needs, including:

- Health professionals' lack of understanding of intellectual disability, and lack of implementation of human-rights, inclusive and evidence-based approaches within healthcare settings
- Negative attitudes or assumptions about people with an intellectual disability, including a false assumption that some people with an intellectual disability cannot make decisions or give informed consent
- Lack of flexibility and reasonable adjustments to meet a person's needs
- A siloed approach to healthcare management that does not recognise the complexity of health-related issues that people with an intellectual disability may experience, which may involve accessing care from several departments that do not interface well.[72]

As a result of the lack of inclusivity within healthcare services, research shows that people with an intellectual disability experience significantly poorer health outcomes compared to other people with disability and people without disability, including:

- More than twice the rate of avoidable deaths
- Twice the rate of emergency department and hospital admissions
- Substantially higher rates of physical and mental health conditions—while simultaneously lower rates of detection of illness, particularly of mental illness
- Significantly lower rates of preventative healthcare and underdiagnosis of chronic and acute health conditions.[73]

In terms of mental health, it is estimated that more than half (57%) of people with an intellectual disability also have a mental health condition.[74] However, across Australian states and territories, people with an intellectual disability are largely excluded from mental health policy and not recognised in healthcare settings as having an increased risk of experiencing mental ill-health.[75]

Diagnostic overshadowing is a significant barrier for people with an intellectual disability to receive appropriate support for mental ill-health. This is the tendency for medical practitioners to consider expressions of pain (including psychological pain) as 'behaviour' or attributable to a disability diagnosis, rather than a clinical issue requiring treatment.[76] This is a critical consequence of the widespread lack of understanding and skills of many health professionals in treating people with an intellectual disability, which contributes to the shorter life expectancy and high rates of preventable deaths among people with an intellectual disability.

Indeed, it is now well understood that training on the health of people with an intellectual disability in Australian university medical and nursing schools is very low, containing:

- A median of 2.6 hours' compulsory content across 12 medical schools
- No intellectual disability content in 52 percent of nursing schools and very limited content overall.[77]

Disability Royal Commission recommendations for government priority

This reflects what was heard by the Disability Royal Commission, which notes in its Final Report that people with an intellectual disability "are subject to systemic neglect in the Australian healthcare system".[78]

Volume 6 of the Final Report puts forward a comprehensive overview of important evidence about how the current health and mental health care systems are failing people with an intellectual disability.

The Commissioners emphasised the need to build the capability of the health workforce to understand and respond to the different needs of people with disability, and embed the right to equitable access to health services in the policy backbone of the health system (its national standards). This includes ensuring that the health system is prepared to engage in preventative health care—in accessible, inclusive and person-centred ways—to reduce the higher risk of mortality for people with an intellectual disability in particular.

We therefore urge the government to implement the following recommendations as a matter of priority.

Importantly, these recommendations reflect and build on the work currently being undertaken by the recently launched National Centre of Excellence in Intellectual Disability Health (the Centre), which will be a crucial catalyst for action to ensure that people with an intellectual disability have improved access to quality, timely and comprehensive healthcare.

In particular, we wish to emphasise the need for urgent action to:

- Improve and implement the 'cognitive disability health capability framework', which will be foundational for further codesign work to include other groups (beyond people with an intellectual disability) in the scope of the Centre's work, as **Recommendation 6.30** explains.
- Implement **Recommendation 6.33** in relation to developing specialised health and mental health services for people with an intellectual disability.

Recommendation 6.24 Improve implementation planning and coordination for the cognitive disability health capability framework

The Australian Government Department of Health and Aged Care should:

- expand the role of the Intellectual Disability Education and Training Expert Advisory Group to develop an implementation plan for the cognitive disability health capability framework, including key steps for embedding the capabilities from the framework in curricula in education and training programs for health practitioners across all training stages.
- develop a monitoring and evaluation framework to coordinate and measure delivery of the expanded capability framework and its implementation.

Recommendation 6.25 Expand the scope of health workforce capability to include all forms of cognitive disability at all stages of education and training

The Australian Government Department of Health and Aged Care should:

- immediately expand the scope of the work on an intellectual disability health capability framework and associated resources to address all forms of cognitive disability, to apply at all stages of education and training. This expansion should include autism-specific content, and address specific healthcare issues for people with learning disability, dementia and acquired brain injury.
- allocate additional funding to support the expanded scope of health workforce capability development.

Recommendation 6.29 Improve specialist training and continuing professional development in cognitive disability healthcare

Continued in full on page 28-29 of Volume 6: https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Volume%206%2C%20Enabling%20autonomy%20and%20access.pdf

Recommendation 6.33 Develop specialised health and mental health services for people with cognitive disability

State and territory governments should establish and fund specialised health and mental health services for people with cognitive disability to provide:

- specialist assessment and clinical services, including preventive medicine, for people with cognitive disability and complex or chronic health and mental health needs
- training and support for health providers to build their capacity to provide safe, high-quality health care to people with cognitive disability.

These services should be delivered through a model that includes:

- specialist roles and multi-disciplinary teams embedded in local health service delivery
- statewide specialised services that can be accessed by people with cognitive disability and health professionals regardless of their location
- participation in a national network of specialised disability health and mental health services
- evaluation of the impact of specialised services and publication of evaluation findings.

Planning to implement specialised services in each jurisdiction should begin as soon as practicable and take into account existing services and needs in each jurisdiction. These changes should be introduced by September 2026.

Restrictive practices

Select key recommendations from the Disability Royal Commission for government priority

Use and impact of restrictive practices

Evidence from the Disability Royal Commission showed that people with an intellectual disability, especially people with complex support needs, are among the most likely to experience restrictive practices, especially chemical restraint.[79]

Research indicates that restrictive practices are routinely used in group homes, [80] and the DRC heard that their use in group homes is increasing.[81] Restrictive practices may also be used in the community, such as in day programs or other disability service settings.

People with disability in detention settings, which includes a high number of First Nations people with an intellectual disability, are also at a high risk of restrictive practices. Prisoners and youth detainees with disability, particularly people with an intellectual disability, are disproportionately secluded in solitary confinement for long periods of time.[82]

The use of medication to restrain people with disability is one form of restrictive practice that is enabled by the health system and common in mental health settings.[83] There is research that indicates medication is given to people with disability as a matter of routine, without any or sufficient therapeutic purpose to explain its use.[84] In Public hearing 6—psychotropic medications, behaviour support and behaviours of concern, Commissioners heard that the number and dosage levels of such medications administered to people with an intellectual disability are sometimes so significant, they constitute abuse.[85]

Further, research commissioned by the Disability Royal Commission stated: “the research literature is unequivocal: people with disability are subject to the greatest use of restrictive practice in segregated and congregated contexts where people with disability are clustered together.”[86]

The report suggested that people with disability’s lack of choice and autonomy within those settings is a distinguishing factor that contributes to the increased use of restrictive practices. As we have pointed out, people with an intellectual disability are more likely to experience life in such settings.

In response to this evidence, we urge the government to immediately implement the following recommendation from the Disability Royal Commission, cited below. These are **Recommendations 6.35, 6.36 and 6.38.**

However, we would advise government that there is a significant (and increasing) range of evidence that would also support the immediate cessation of some restrictive practices—plus the full resourcing and implementation of other evidence-based preventative measures to reduce or avoid the use of restrictive practices—in other settings in which people with disability are grouped together, separate from the community. This includes **group homes and ADEs.** To this list we would also add a number of closed settings (beyond the health and mental health settings listen in the recommendation) such as any setting associated with criminal justice contexts, including **prisons and youth detention.**

This is because of the mounting evidence that demonstrates:

1. **Restrictive practices are at odds with international human rights obligations**
    - There is an absolute prohibition on torture and cruel, inhuman or degrading treatment or punishment under international law. This means that restrictive practices that rise to the level of torture and cruel, inhuman or degrading treatment or punishment must be prohibited. Further, there are strong human rights obligations relating to prohibition of discrimination against people with disability and rights to protection from violence.
    - Given that restrictive practices represent a form of violence that is applied on a discriminatory basis to people with disability, then these practices, even where they do not rise to the level of torture and cruel, inhuman or degrading treatment or punishment, are at odds with international law.

2. **Restrictive practices strip people with disability of dignity**
    - The principle of dignity is at the core of international human rights obligations to prevent torture and ill-treatment, protections from violence, and equality and non-discrimination. Use of restrictive practices fails to respect the inherent dignity of people with disability. Analysis in DRC research of the lived experiences accounts researchers collected shows that people with disability experience restrictive practices in the following interconnected ways:
        - Trauma, pain, harm and violence
        - Abandonment and neglect
        - Fear
        - Disempowering, humiliating and dehumanising
        - Cruel and punishing treatment
        - Lifelong trauma and life-altering effects.

3. **People with an intellectual disability, specifically those with complex needs, experienced an increased risk of restrictive practices, especially chemical restraint.**
    - While there may be some uncertainty in Australia about whether some practices might be considered torture or ill-treatment, the guidance from the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment states “it is essential that an absolute ban on people with psychological or intellectual disabilities should apply in all places of deprivation of liberty, including psychiatric and social care institutions”.[87]

Recommendation 6.36 Immediate action to provide that certain restrictive practices must not be used

State and territory governments should immediately:

- Adopt the list of prohibited forms of restrictive practices agreed by the former Disability Reform Council in 2019 and provide that the use of seclusion on children and young people is not permitted in disability service settings.
- Provide that the following are not permitted in health and mental health settings:
    - using seclusion and restraint as a means to reduce behaviours not associated with immediate risk of harm
    - using seclusion and restraint as a form of discipline, punishment or threat
    - restrictive practices that involve or include deliberate infliction of pain to secure compliance
    - using prone or supine holds, using any restraint intended to restrict or affect respiratory or digestive function, or forcing a person's head down to their chest
    - secluding a person who is also mechanically restrained
    - secluding a person who is actively self-harming or suicidal using metal handcuffs or hard manacles as a form of mechanical restraint (unless under police or other custodial supervision while in the health facility)
    - vest restraints for older people
    - neck holds
    - drugs, or higher doses of drugs, that create continuous sedation to manage behaviour
    - seclusion of children and young people.

Continued on page 516 of Volume 6, Disability Royal Commission Final Report:
https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Volume%206%2C%20Enabling%20autonomy%20and%20access.pdf

Recommendation 6.35 Legal frameworks for the authorisation, review and oversight of restrictive practices

a. States and territories should ensure appropriate legal frameworks are in place in disability, health, education and justice settings, which provide that a person with disability should not be subjected to restrictive practices, except in accordance with procedures for authorisation, review and oversight established by law.

b. The legal frameworks should incorporate the following requirements, appropriately adapted to sector-specific contexts.

- Restrictive practices should only be used:
  - as a last resort, in response to a serious risk of harm to a person with disability or others, and only after other strategies, including supported decision-making, have been explored and applied
  - as the least restrictive response possible to ensure the safety of the person with disability or others
  - to the extent necessary to reduce the risk of harm and proportionate to the potential negative consequences from the use of restrictive practices
  - for the shortest time possible.

Continued on page 513 of Volume 6, Disability Royal Commission Final Report:
https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Volume%206%2C%20Enabling%20autonomy%20and%20access.pdf

Recommendation 6.38 Strengthening the evidence base on reducing and eliminating restrictive practices

The National Disability Research Partnership should commission a longitudinal study of the impact of positive behaviour support and other strategies to reduce and eliminate restrictive practices. This study should:

- be co-designed with people with disability and relevant experts and professionals from the disability, health, education and justice sectors, to ensure the findings are relevant across a range of settings
- include the experiences and identify the intersecting needs of a broad range of people with disability, such as First Nations people with disability, LGBTIQA+ people with disability, and culturally and linguistically diverse people with disability.

Upon completion, the findings of the study should be made publicly available. Interim findings should be published at regular intervals.

Gaps in Disability Royal Commission recommendations in relation to restrictive practices and behaviour support

Unfortunately, there is a dearth of recommendations or discussion related to behaviour support in the Disability Royal Commission's Final Report. This is despite the significant evidence about the need and prerequisites of good quality behaviour support heard across a range of the Disability Royal Commission's hearings, submissions and research program, including:

- Public hearing 6—psychotropic medication, behaviour support and behaviours of concern
- Safeguards and Quality Issues Paper
- Restrictive Practices Issues Paper
- The University of Melbourne, University of Technology Sydney, and the University of Sydney: Restrictive practices: a pathway to elimination, a research report commissioned by the Disability Royal Commission.

We wish to highlight some key (yet non-exhaustive) findings gleaned from this body of evidence. We believe they demonstrate the need for government to acknowledge the gap in the Disability Royal Commission's Final Report in relation to behaviour support practices, and work with organisations in the sector to devise strategies that meaningfully respond to the findings set out below.

Brief evidence review—changing understandings of 'behaviour of concern'

The evidence highlights the widespread need across the community to shift our understandings of behaviour—and especially so-called 'behaviours of concern'—to recognise them as both a product of the interactions between the person and their environment, and as socially constructed.[88]

It is becoming widely accepted that 'behaviours of concern' is a culturally, and potentially, setting-specific "socially constructed, dynamic concept", which reflects dominant social attitudes towards people with disability, and which requires someone else to consider the behaviour of a person with disability, and to interpret it as "dangerous, frightening, distressing or annoying".[89]

For example, one UK study found that people with intellectual disability engage in 'acts of resistance' in relation to their restrictive environments.[90] These acts of resistance are reconstructed by staff as 'behaviours of concern', and subsequently used to legitimatise staff use of restrictive practices and referral of those people with intellectual disability to other health professionals.

It is also well understood that 'behaviours of concern' are an important and valid part of a person's communication—this is true for people with and without disability. As Bradley and Korossy state in their 2016 study, 'behaviours of concern' "can best be considered as communications of distress by individuals unable to communicate their distress in more conventional ways".[91]

Importantly for the purpose of the Disability Royal Commission's recommendations, research has shown that "restrictive practices may form part of a 'vicious cycle' in which the psychological instability and distress they generate leads to more behaviours that in turn result in further restrictive practices".[92]

Paul Ramcharan and colleagues also note that "behaviours of concern may equally define the service, rather than being pathologically and unidirectionally attributed to people with disabilities"[93] and that “a behaviour of concern is **likely to be produced by ‘an environment of concern’** … behaviours seen as being ‘of concern’ can be understood better as adaptive behaviours to maladaptive environments … and should be seen as legitimate responses to difficult environments and situations, and not a reason for restrictions designed to change the person and their behaviour”.[94]

This was a key finding of the research report commissioned by the Disability Royal Commission authored by Spivakovsky et al., which found that restrictive practices (as responses to ‘behaviours of concern’) take place within an “ecological system of violence, coercion, and control”.[95]

That is, relationships between people with disability and those who support them take shape in institutional and organisations contexts. According to this research report, **“the research literature is unequivocal: people with disability are subject to the greatest use of restrictive practices in segregated and congregated contexts where people with disability are clustered together”.[96]** The authors also found that people with disability’s lack of choice and autonomy within those settings is a distinguishing factor that contributes to the increased use of restrictive practices. The diagram below demonstrates the interconnected systems and environments that perpetuate these practices.

We note that Spivakovsky et al. also put forward an ‘Eight-point action plan’ to eliminate restrictive practices, which we believe must be considered by government in conjunction with the additional recommendations set out on the following page.

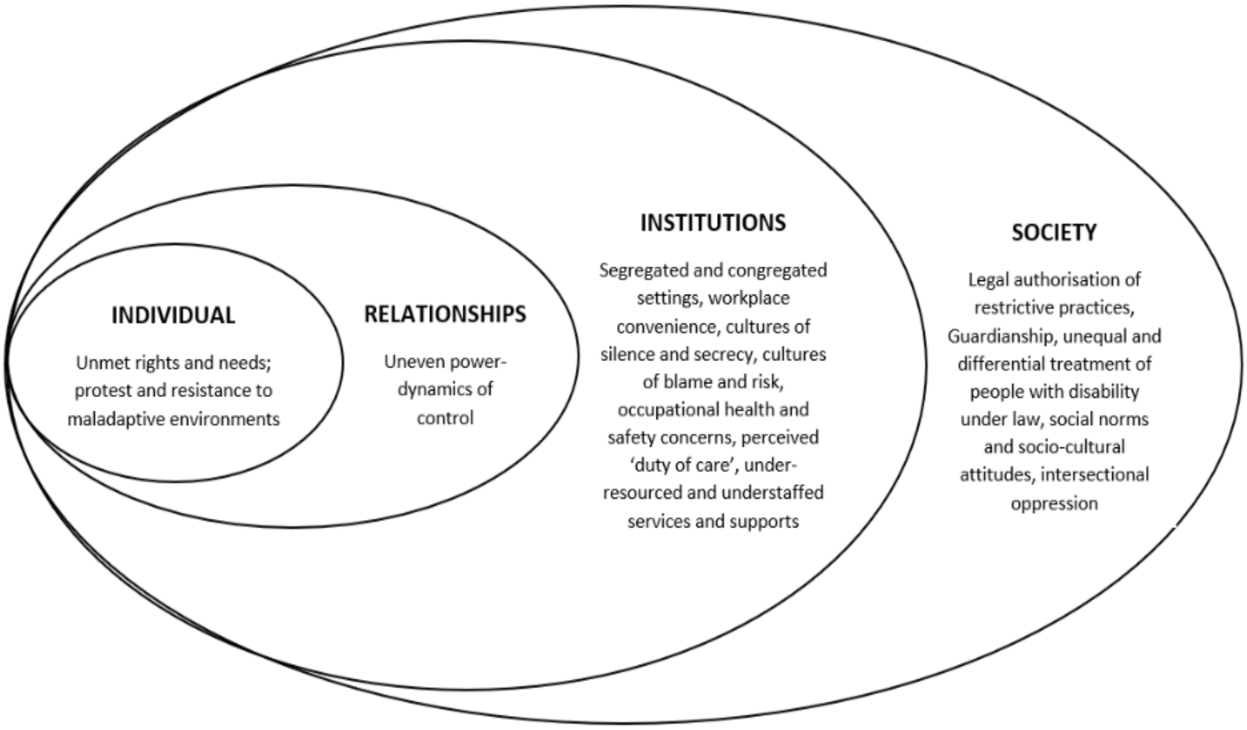


Figure 1: The ecological system of restrictive practices as identified by people with disability.

Source: Spivakovsky, Claire., Steele, Linda., and Wadiwel, Dinesh. 2023. Restrictive practices: a pathway to elimination. A research report commissioned by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. University of Melbourne, Australia. Page 6.

What does this mean for the government's response to the Disability Royal Commission?

We believe that this evidence demonstrates the need for targeted strategies that work to address the pathologisation of 'behaviour' and the ways this incentivises the use, and in many cases over-use,[97] of restrictive practices—particularly for people with complex needs.

Yet contemporary research into the use of restrictive practices and what constitutes 'best practice' in behaviour support is marked by several limitations. There has been very little scholarly research into the experiences of people with disability who are subject to restrictive practices, with a few notable exceptions.[98] These limitations mean that the evidence-base for behaviour support, including Positive Behaviour Support, can be considered 'emerging' rather than 'established'.[99]

Spivakovsky et al. describe the extent of those limitations:

> *There has also been little to no research into the specific experiences of restrictive practices for LGBTQIA+ people with disability, or culturally and linguistically diverse people with disability Only a few studies consider the experiences of First Nations people with disability. Additionally, while people with disability's experiences of some forms of restrictive practices are well explored—such as experiences of seclusion or involuntary mental health treatment—experiences of other forms of restrictive practice such as guardianship or financial management are rarely considered. This disparity in accounts is at least in part reflective of the opportunities that have and have not been provided to people with different types of disability to articulate experiences of restrictive practices over the years. Very few researchers venture into group homes to speak with people with disability, and, to the best of our knowledge, little to no attempts have been made to capture the accounts of people with disability subject to restrictive practices in the context of Australian Disability Enterprises, day programs, out-of-home-care, immigration detention, and in the family home.*

It is also important to note that many of the 'high level' frameworks and principles for reducing and/or eliminating restrictive practices that exist in Australia across a range of settings are sorely under researched in terms of their effectiveness.[100] Any evaluation or consideration of these frameworks have occurred in the context of mental health settings alone.

We therefore believe the government must facilitate the promotion of effective practices in relation to behaviour support and the reduction and ultimately elimination of restrictive practice. **To do this, more independent evaluation and research is urgently needed.** Given the evidence set out above, we believe an immediate and long-term investment in such research activities should be a priority for government in developing its response to the Disability Royal Commission.

Additional recommendations to implement as part of Recommendations 6.35, 6.36 and 6.38

- Invest in research activities co-designed with people with an intellectual disability and their families—with an emphasis on including people residing in segregated or closed settings such as group homes, ADEs and criminal justice settings—to increase the evidence-base in relation to behaviour support and the elimination of restrictive practices.

Access to behaviour support practitioners

Volume 10 of the Disability Royal Commission's Final Report makes a recommendation about the need to ensure greater access to behaviour support practitioners.

We support this recommendation in full. However, we are concerned that it is too narrow in scope and will not be efficacious in addressing many of the issues raised above.

Volume 10 also relays what was heard in relation to the often-poor quality of behaviour support plans, which do not always comply with regulatory requirements and do not "reflect a positive and strengths-based approach to people with a disability".[101]

As such, we make additional recommendations which we believe should be implemented by government in conjunction with **Recommendation 10.24.**

Recommendations 10.24 Improved access to behaviour support practitioners

The NDIS Quality and Safeguards Commission should, by December 2024, improve access to behaviour support practitioners by:

a. providing incentives for practitioners and National Disability Insurance Scheme providers to provide behaviour support services, including in regional and remote areas in which 'thin markets' operate

b. forming a partnership with First Nations leaders from the disability and employment services sectors to develop a recruitment strategy targeting First Nations people and others with experience in working with First Nations communities to address behaviour support shortages in regional and remote areas

c. exploring with behaviour support practitioners, service providers and people with disability, the merits of an 'on-the-job' professional development and accreditation model for behaviour support practitioners

d. creating a publicly accessible list of all individual behaviour support practitioners.

Additional recommendations to implement as part of Recommendations 10.24

- **Require that the person is meaningfully involved in the development of their own support plans through access to Supported decision-making**

  Involving the person in the development of their own behaviour support plan (BSP) (often referred to in the literature as 'co-production') is a critical tenet of a person-centred framework.

  Involving the person in their BSP recognises people with disability as experts of their own lives, as well as promoting choice and control and ownership of decisions and strategies to improve quality of life. One way of establishing this as a practice would be by embedding a Supported decision-making framework in the BSP.

  'Co-production' is increasingly being recognised as best practice to achieve quality across many social care settings. Introducing a requirement to provide evidence about how the individual was involved in the development of their BSP would bring the BSPs in line with international best practice.

- **Behaviour support plans must promote trusting relationships between the person and their supporters**

  BSPs must facilitate trusted relationships between behaviour support practitioners, other supporters, and the person. Getting to know a person and understanding their context must be prioritised in order to effectively understand and meaningfully address behaviours.

  BSPs need to account for each persons' unique lives, histories, needs and aspirations—this can be achieved by facilitating relationships and prompting opportunities for the behaviour support practitioner(s) to get to know the person in a meaningful way.

  Given what we know about the prevalence of systemic violence and trauma experienced among people with an intellectual disability, plus current evidence on the ways in which trauma underlays behaviour, it is crucial that BSPs facilitate meaningful and trusted relationships to ensure that, if applicable, trauma is appropriately recognised when developing strategies for behaviour support.

  BSPs need to promote better understandings of the ways a person's environment affects behaviours. That is, understanding challenging behaviours requires knowledge about the context in which they occur (and do not occur), and this should be developed over time through establishing trust and building relationships so that behaviour support practitioners can get to know the person and their history in a meaningful way.

  In this way it becomes possible to understand underlying drivers of behaviour, such as unmet needs, communication barriers or underlying trauma responses. This creates opportunities for person-centred support that promotes peoples' strengths and works proactively **with the person** and their family members or other supporters to find holistic solutions to challenging behaviour, rather than reacting to the behaviour alone.

  This also means that BSPs need to be active and able to be changed. This reflects the fluid, changing circumstances of all peoples' lives—no one's behaviour or life circumstances are fixed, and the BSPs must reflect this.

Additional recommendations to implement as part of Recommendations 10.24 (continued)

- **Behaviour support plans must be devised in accessible formats that make sense to the person**

  BSPs are typically written at a reading level well above that of the staff implementing them. Further, using language that makes sense to the person the BSP is supporting is critical in ensuring the plan is genuinely person-centred and has been developed with the person in a meaningful way.

Transport

While federal, state and territory governments have done important work to increase the accessibility of public transport for people with disability, major gaps remain.

Nationally, only half of Australia's public transport infrastructure meets accessibility standards.[102] Levels of accessibility in public transport systems vary widely across jurisdictions, reflecting the lack of accountability and enforcement of the Standards in all states and territories.

Recent figures show that 40% of Queensland and Western Australia's train stations, 73% of Victoria's trams, and one-third of train and ferry stations in New South Wales are not accessible.[103]

This means that all around Australia, people with disability are shut out from crucial means of accessing essential services, employment opportunities and ordinary participation in society on equal basis with others.

The impacts of these inequities are far reaching: the inaccessibility of public transport is socially and economically disabling, and—as many recent news stories from people with disability attest[104]—inaccessible public transport creates and exacerbates experiences of isolation and diminishes self-determination. It is both a human rights issue and a matter of public health and safety.[105]

Accessible transport is also an important facilitator of inclusion. It is the means by which people can independently leave their house and join other people in the community. It is the facilitator of employment, education and other critical economic and social inclusions.

The absence of transport and transport training in NDIS plans is a key barrier to an inclusive life.

We are very concerned that transport was not addressed in the Disability Royal Commission's Final Report. We see this as being a major gap which needs to be urgently addressed by government in its response to the Disability Royal Commission's recommendations.

Our transport systems are not public until everyone can use them.

In 2023, we participated (along with many of our member organisations) in the national consultation regarding the 2022 Review of the Disability Standards for Accessible Public Transport 2022. Our submission can be found here.

We made a number of recommendations in that submission, which we believe should be implemented by government as part of its response to the Disability Royal Commission.

Additional recommendations to implement as part the government's response to the Disability Royal Commission in relation to transport

- Include the rights of people with an intellectual disability in the Disability Standards for Accessible Public Transport 2002
- Ensure all information and communication relating to public transport must be freely available in inclusive formats such as Easy Read
- Implement mandatory testing of all new public transport systems by people with intellectual disability, and ensure people are paid for doing so
- Ensure public transport is safe for all people, including people with an intellectual disability
- Enforce greater accountability and enforcement of the Standards is urgently needed across all states and territories.
- There should be separate, co-designed standards for air travel.

Appendix A

Evidence from the Disability Royal Commission demonstrating that people with an intellectual disability are more likely to experience a range of forms of violence, abuse, neglect and exploitation, compared with other people with disability in Australia.

Australian Institute of Health and Welfare. 2022. *People with disability in Australia—Income.* Retrieved from https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia

McVilly, K., Ainsworth, S., Graham, L., Harrison, M., Sojo, V., Spivakovsky, C., Gale, L., Genat, A., Zirnsak, T. (2022). Outcomes associated with 'inclusive', 'segregated' and 'integrated' settings: Accommodation and community living, employment and education. A research report commissioned by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. University of Melbourne, Australia. Page 120.

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. 2023. Executive Summary: Our vision for an inclusive Australia and Recommendations. Page 124. Retrieved from: https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Executive%20Summary%2C%20Our%20vision%20for%20an%20inclusive%20Australia%20and%20Recommendations.pdf., p. 84-85.

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. 2020. Report on Public hearing 6: Psychotropic medication, behaviour support and behaviours of concern. Retrieved from: https://disability.royalcommission.gov.au/publications/report-public-hearing-6-psychotropic-medication-behaviour-support-and-behaviours-concern

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. 2023. Executive Summary: Our vision for an inclusive Australia and Recommendations. Page 124. Retrieved from: https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Executive%20Summary%2C%20Our%20vision%20for%20an%20inclusive%20Australia%20and%20Recommendations.pdf

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. 2020. Report on Public hearing 6: Psychotropic medication, behaviour support and behaviours of concern. Retrieved from: https://disability.royalcommission.gov.au/publications/report-public-hearing-6-psychotropic-medication-behaviour-support-and-behaviours-concern

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. 2020. Public hearing 4: Health care and services for people with cognitive disability. Retrieved from: https://disability.royalcommission.gov.au/system/files/2020-10/Report%20-%20Public%20hearing%204%20-%20Healthcare%20for%20people%20with%20cognitive%20disability.pdf.

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Transcript, Professor Nicholas Lennox, Public Hearing 4, 25 February 2020, P-561 [19]–[31]

Exhibit 4-21, ‘Statement of Professor Nicholas Gordon Lennox’, 11 February 2020 at [53]–[57].

Spivakovsky, Claire., Steele, Linda., and Wadiwel, Dinesh. 2023. Restrictive practices: a pathway to elimination. A research report commissioned by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. University of Melbourne, Australia.

Troller, J., and Small, J. (2019). Health Inequality and People with Intellectual Disability—Research Summary. Retrieved from: https://cid.org.au/wp-content/uploads/2019/07/Research-Analysis-Health-Status-of-People-With-Intellectual-Disability.pdf

Vincent, J., McCarthy, D., Miller, H., Armstrong, K., Lacey, S., Lian, G., Qi, D., Richards, N., Berry, T. (2022). Research Report - The economic cost of violence, abuse, neglect and exploitation of people with disability. Taylor Fry. Retrieved from: https://disability.royalcommission.gov.au/system/files/202309/Research%20Report%20%20Economic%20cost%20of%20violence%2C%20abuse%2C%20neglect%20and%20exploitation%20of%20people%20with%20disability.pdf

Wilson, E. and Campain, R. 2020. ‘Fostering employment for people with an intellectual disability: the evidence to date’, Hawthorn, Centre for Social Impact, Swinburne University of Technology.

Reference List

---

[1] https://disability.royalcommission.gov.au/publications/final-report-executive-summary-our-vision-inclusive-australia-and-recommendations

[2] McVilly, K., Ainsworth, S., Graham, L., Harrison, M., Sojo, V., Spivakovsky, C., Gale, L., Genat, A., Zirnsak, T. (2022). Outcomes associated with 'inclusive', 'segregated' and 'integrated' settings: Accommodation and community living, employment and education. A research report commissioned by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. University of Melbourne, Australia. Page 120.

[3] McVilly, K. et al. 2022. Outcomes associated with 'inclusive', 'segregated' and 'integrated' settings.

[4] 'Cognitive impairment' is an umbrella term used by the Disability Royal Commission. It describes a range of cognitive disabilities, including intellectual disability.

[5] Ibid.

[6] Vincent, J., McCarthy, D., Miller, H., Armstrong, K., Lacey, S., Lian, G., Qi, D., Richards, N., Berry, T. (2022). Research Report - The economic cost of violence, abuse, neglect and exploitation of people with disability. Taylor Fry. Retrieved from: https://disability.royalcommission.gov.au/system/files/202309/Research%20Report%20%20Economic%20cost%20of%20violence%2C%20abuse%2C%20neglect%20and%20exploitation%20of%20people%20with%20disability.pdf

[7] Researchers used this term to denote the increased likelihood of people with disability experiencing a poorer outcome, or range of outcomes, relative to the general population. The outcomes gap can also be understood as an over-representation of people with disability among people experiencing poor outcomes overall. The cost of the outcomes gap is high but the forms of maltreatment that likely contribute to it are hard to quantify and/or often not recorded in administrative datasets.

[8] Vincent, J. et al. The economic cost of violence, abuse, neglect and exploitation of people with disability, p 3.

[9] Ibid., p. 3.

[10] Ibid., p. 3.

[11] Troller, J., and Small, J. (2019). Health Inequality and People with Intellectual Disability—Research Summary. Retrieved from: https://cid.org.au/wp-content/uploads/2019/07/Research-Analysis-Health-Status-of-People-With-Intellectual-Disability.pdf

[12] Vincent, J. et al. The economic cost of violence, abuse, neglect and exploitation of people with disability, p 3.

[13] Ibid.

[14] McVilly, K. et al. 2022. Outcomes associated with 'inclusive', 'segregated' and 'integrated' settings. p. 120.

[15] Ibid.

[16] Disability Royal Commission. 2023. Final Report – Volume 7. Retrieved from: https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Volume%207%2C%20Inclusive%20education%2C%20employment%20and%20housing%20-%20Summary%20and%20recommendations.pdf p. 55.

[17] https://disability.royalcommission.gov.au/system/files/2023-11/Final%20report%20-%20Executive%20Summary%2C%20Our%20vision%20for%20an%20inclusive%20Australia%20and%20Recommendations.pdf

[18] Ibid.

[19] Inclusion Australia. (2021). *What Works: Making Disability Employment Services (DES) work for people with an intellectual disability*. https://www.inclusionaustralia.org.au/wp-content/uploads/2022/02/Our-Submissions_2022_02_What-Works-Final-Report-2021.pdf;

Inclusion Australia. (2022). *DES Reform Submission.* https://www.inclusionaustralia.org.au/wp-content/uploads/2022/03/Our-Submissions_2022_02_Submission-on-Disability-Employment-System-Reform.pdf;

Inclusion Australia. (2023). Disability Employment Services Quality Framework. https://www.inclusionaustralia.org.au/submission/disability-employment-services-quality-framework; and

---

People with Disability Australia. (2022). *Joint Submission—Employment White Paper: Submission to the Australian Treasury's Employment White Paper.* https://www.inclusionaustralia.org.au/wp-content/uploads/2022/12/FINAL_SUB_Employment-White-Paper_14122022.pdf

[20] Labour Market Information Portal DES Data 30 November 2021.

[21] Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of Findings, 2019. Retrieved from: https://www.abs.gov.au/statistics/health/disability/disability-ageing-andcarers-australia-summary-findings/latest-release 2021.

[22] Ibid., see also: Wilson, E. and Campaign, R. (2020). Fostering employment for people with intellectual disability: the evidence to date. Centre for Social Impact, Swinburne University of Technology. Retrieved from: https://www.everyonecanwork.org.au/wp-content/uploads/2020/11/Fostering-employment-for-people-with-intellectual-disability-Accessible.pdf

[23] National Disability Insurance Agency (NDIA) (2019). People with an intellectual disability in the NDIS. https://data.ndis.gov.au/reports-and-analyses/people-intellectual-disability-ndis.

[24] Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of Findings, 2019. Retrieved from: https://www.abs.gov.au/statistics/health/disability/disability-ageing-andcarers-australia-summary-findings/latest-release 2021

[25] Cocks, E. & Harvey, T.(2008). Employment/Day Options Interface Research Project. Final Report, Perth, Curtin University of Technology, School of Occupational Therapy and Social Work., https://espace.curtin.edu.au/bitstream/handle/20.500.11937/43977/135257_18935_Employment%20Day%20Options%20Final%20Report.pdf?sequence=2&isAllowed=y

[26] People with an intellectual disability in the NDIS," in NDIS, <https://data.ndis.gov.au/reports-and analyses/participant-groups/people-intellectual-disability-ndis> [accessed 6 September 2022]

[27] Australian Federation of Disability Organisations. (2018). AFDO – Position paper on the future of supported employment. https://engage.dss.gov.au/wp-content/uploads/2018/03/AFDO-Future-of-Supported-Employment-Paper-2018-03-FINAL.pdf

[28] https://www.inclusionaustralia.org.au/wp-content/uploads/2023/05/Equal-Pay-Equal-Rights-Final-DRC-submission-December-2022.pdf

[29] Ibid.

[30] The Australian Government submitted to the Disability Royal Commission that it is 'technically incorrect' to characterise wages paid in accordance with the SES award as 'subminimum wages.' However, the Commissioners stated that it is the "fairness of the legal position that is in issue", and adopt the term 'subminimum wages' to describe a wage below the national minimum. The term is also used by the CRPD Committee.

[31] Taylor Fry and the Centre for International Economics. 2023. Costing a Transition Away from Subminimum Wages. Retrieved from: https://disability.royalcommission.gov.au/publications/costing-subminimum-wage-subsidy; and Taylor Fry and the Centre for International Economics. 2023. Additional costing half minimum wage subsidy. Retrieved from: https://disability.royalcommission.gov.au/publications/additional-costing-half-minimum-wage-subsidy

[32] The DSP provides an income for single people with disability of $936.80 per fortnight, with an additional pension supplement ($75.60) and energy supplement ($14.10) per fortnight.
Department of Social Services (February 2023). *Social Security Guide.* Version 1.303. Retrieved from www.guides.dss.gov.au/ social-security-guide/3/6/2/50

[33] https://www.inclusionaustralia.org.au/wp-content/uploads/2023/05/Equal-Pay-Equal-Rights-Final-DRC-submission-December-2022.pdf

[34] Disability Royal Commission. 2023. Final Report – Volume 7: Inclusive education, employment and housing, Part C. Retrieved from: https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Volume%207%2C%20Inclusive%20education%2C%20employment%20and%20housing%20-%20Part%20C.pdf p. 617.

[35] Ibid, p. 631.

[36] Ibid., p. 632.

[37] See Tune Review (p. 120) for more: https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf

---

[38] Vincent, J., McCarthy, D., Miller, H., Armstrong, K., Lacey, S., Lian, G., Qi, D., Richards, N., Berry, T. (2022). Research Report - The economic cost of violence, abuse, neglect and exploitation of people with disability. Taylor Fry. Retrieved from: https://disability.royalcommission.gov.au/system/files/202309/Research%20Report%20%20Economic%20cost%20of%20violence%2C%20abuse%2C%20neglect%20and%20exploitation%20of%20people%20with%20disability.pdf

[39] McVilly, K., Ainsworth, S., Graham, L., Harrison, M., Sojo, V., Spivakovsky, C., Gale, L., Genat, A., Zirnsak, T. (2022). Outcomes associated with 'inclusive', 'segregated' and 'integrated' settings: Accommodation and community living, employment and education. A research report commissioned by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. University of Melbourne, Australia. Page 120.

[40] Salomon, C. and Troller, J. 2019. A scoping review of causes and contributors to deaths of people with disability in Australia. Commissioned by the NDIS Commission. Retrieved from: https://www.ndiscommission.gov.au/resources/reports-policies-and-frameworks/research-deaths-people-disability/2019-report-scoping

[41] Ibid.

[42] Transcript, Pauline Bagdonavicius, Public hearing 30, 21 November 2022, P-101 [7–21]; STAT.0663.0001.0030, Statement in response to the notice to give a statement in writing to Pauline Bagdonavicius, Public Advocate, WA, pp 31-32, [169–75]. https://disability.royalcommission.gov.au/public-hearings/public-hearing-30-guardianship-substituted-and-supported-decision-making

[43] Disability Royal Commission. 2023, Final Report—Volume 6: Enabling autonomy and access. Retrieved from: https://disability.royalcommission.gov.au/publications/final-report-volume-6-enabling-autonomy-and-access

[44] Salomon, C. and Troller, J. 2019. A scoping review of causes and contributors to deaths of people with disability in Australia. Commissioned by the NDIS Commission. Retrieved from: https://www.ndiscommission.gov.au/resources/reports-policies-and-frameworks/research-deaths-people-disability/2019-report-scoping

[45] Ibid.

[46] Salomon, C. and Troller, J. 2019. A scoping review of causes and contributors to deaths of people with disability in Australia. Commissioned by the NDIS Commission. Retrieved from: https://www.ndiscommission.gov.au/resources/reports-policies-and-frameworks/research-deaths-people-disability/2019-report-scoping

[47] https://disability.royalcommission.gov.au/public-hearings/public-hearing-24-experience-children-and-young-people-disability-different-education-settings

[48] Ibid.

[49] Children and Young People with Disability Australia. 2018. Supported School Transport and transition to the National Disability Insurance Scheme. Retrieved from: https://cyda.org.au/wp-content/uploads/2023/08/supported_school_transport_ndis-1.pdf

[50] Disability Royal Commission. 2023. Transcript Day 4: Public hearing 24: The experience of children and young people with disability in different education settings. Retrieved from: https://disability.royalcommission.gov.au/public-hearings/public-hearing-24-experience-children-and-young-people-disability-different-education-settings-canberra-day-3

[51] Ibid.

[52] Baxter, J. 2021. Couples sharing child care: the COVID19 experience. The Australian Institute of Family Studies Conference. Retrieved from: https://aifs2022.paperlessevents.com.au/share/Baxter-97#iframe

[53] https://disability.royalcommission.gov.au/publications/report-public-hearing-12-experiences-people-disability-context-australian-governments-approach-covid-19-vaccine-rollout

[54] See, for example, our project Towards Inclusive Practice; and our recent research report, Engaging with autistic people with an intellectual disability – Inclusion Australia

[55] See, for example, our Everyone Can Work project and CID's project More Than Just A Job.

[56] Disability Royal Commission. 2023. Volume 6—Autonomy and Access. Retrieved from: https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Volume%206%2C%20Enabling%20autonomy%20and%20access.pdf p. 134-135.

[57] Ibid.

---

[58] NSW Trustee and Guardian. 2023. Annual Report: 2022-23. Retrieved from: https://www.tag.nsw.gov.au/sites/default/files/2023-12/NSW%20Trustee%20%26%20Guardian%20Annual%20Report%202022-23.pdf

[59] Transcript, Pauline Bagdonavicius, Public hearing 30, 21 November 2022, P-101 [7–21]; STAT.0663.0001.0030, Statement in response to the notice to give a statement in writing to Pauline Bagdonavicius, Public Advocate, WA, pp 31-32, [169–75]. https://disability.royalcommission.gov.au/public-hearings/public-hearing-30-guardianship-substituted-and-supported-decision-making

[60] NDIS Review. 2023. Working together to deliver the NDIS: Independent Review into the National Disability Insurance Scheme, Final Report. Retrieved from: https://www.ndisreview.gov.au/sites/default/files/resource/download/working-together-ndis-review-final-report.pdf p.108-109.

[61] Ibid.

[62] Ibid.

[63] https://www.inclusionaustralia.org.au/submission/submission-to-the-disability-royal-commission-on-guardianship-and-substituted-decision-making/

[64] https://www.inclusionaustralia.org.au/submission/submission-to-the-disability-royal-commission-on-guardianship-and-substituted-decision-making/

[65] Bigby, C., Carney, T., Then, S-N., Wiesel, I., Sinclair, C., Douglas, J., & Duffy, J., (2023). Diversity, dignity, equity and best practice: a framework for supported decision-making. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability https://disability.royalcommission.gov.au/policy-and-research/research-program. Page 31.

[66] ‘People with complex needs/communication support needs’ or ‘people with high support needs’ are terms used variously throughout various DRC documents. There does not seem to be a guiding definition. Intellectual Disability Mental Health Connect (NSW) says: “people with intellectual disability can have complex needs. While there is no agreed upon definition of complex needs, there are two elements that are consistently mentioned: a) the presence of a disability and other health, social and economic issues and b) a disconnect between support needs and the services available to meet these needs … having multiple needs means that there is often no one framework or service that can support all their needs. This may result in services system fragmentation, poor continuity of care, long waiting times, high costs, unavailable services or not meeting service eligibility requirements”.

[67] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7601275/

[68] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7601275/

[69] https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Volume%206%2C%20Enabling%20autonomy%20and%20access.pdf p. 270.

[70] https://disability.royalcommission.gov.au/system/files/2022-03/Overview%20of%20responses%20to%20the%20Safeguards%20and%20quality%20Issues%20paper.pdf

[71] https://disability.royalcommission.gov.au/system/files/2022-03/Overview%20of%20responses%20to%20the%20Safeguards%20and%20quality%20Issues%20paper.pdf

[72] Troller, J., and Small, J. (2019). Health Inequality and People with Intellectual Disability—Research Summary. Retrieved from: https://cid.org.au/wp-content/uploads/2019/07/Research-Analysis-Health-Status-of-People-With-Intellectual-Disability.pdf

[73] Inclusion Australia. (2020). Inclusion Australia’s Response to the issues paper on healthcare for people with cognitive disability. p. 4. Retrieved from: https://www.inclusionaustralia.org.au/wp-content/uploads/2021/10/Our-Submissions_2020_08_Submission-to-the-DRC-on-healthcare-for-people-with-intellectual-disability.pdf

Inclusion Australia. (2020). Submission to the Disability Royal Commission – The Omnibus. p. 51-54. Retrieved from: https://www.inclusionaustralia.org.au/submission/submission-to-the-drc-the-omnibus/

[74] Troller, J., and Small, J. (2019). Health Inequality and People with Intellectual Disability—Research Summary. Retrieved from: https://cid.org.au/wp-content/uploads/2019/07/Research-Analysis-Health-Status-of-People-With-Intellectual-Disability.pdf

[75] A. Dew, L. Douse, U. Athanassiou, J. Troller, S. Reppermund. (2018). Making Mental Health Policy Inclusive of People with Intellectual Disability. University of New South Wales. www.3dn.unsw.edu.au/sites/default/files/documents/MHID%20Policy%20Review%20Report_final_new%20template.pdf;

Whittle, E. L., Fisher, K. R., Reppermund, S., & Trollor, J. (2019). Access to mental health services: The experiences of people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 32(2), 368–379. https://doi.org/10.1111/jar.12533

[76] K. Pouls, M. Koks-Leensen, M. Mastebroek, G. Leusink, W. Assendelft. (2022). Adults with intellectual disabilities and mental health disorders in primary care: a scoping review. *British Journal of General Practice*, 72(716): e168-e178; A. Javaid, V. Nakata, D. Michael. (2019). Diagnostic overshadowing in learning disability: think beyond the disability. *Progress in Neurology and Psychiatry*, 23(2); J. Mason, K. Scior. (2004). 'Diagnostic Overshadowing' Amongst Clinicians Working with People with Intellectual Disabilities in the UK. *Journal of Applied Research in Intellectual Disabilities*, 17(2): 85-90.

[77] Trollor, J., et al. (2016). Intellectual disability health content within medical curriculum: an audit of what our future doctors are taught. *BMC Medical Education* 16 (105):

[78] https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Volume%206%2C%20Enabling%20autonomy%20and%20access.pdf

[79] Ibid.

[80] Claire Spivakovsky, 'Governing Freedom through Risk: Locating the Group Home in the Archipelago of Confinement and Control' (2017) 19(3) Punishment & Society 374; Lynne Weber, Keith McVilly and Jeffry Chan, 'Restrictive Interventions for People with Intellectual Disability Exhibiting Challenging Behaviours: Analyses of a Population Database' (2011) 24(6) *Journal of Applied Research in Intellectual Disabilities*, pp 495-507.

[81] Ageing and Disability Commission, Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability in response to *Group homes issues paper*, 4 March 2020, at ISS.001.00060, p 10.

[82] Paul Harpur and Heather Douglas 'Disability and domestic violence: protecting survivors' human rights' (2014), 23(3), *Griffith Law Review*, pp 405-433.

[83] Forensicare, *Use of Restrictive practices on males released from prison and entering acute mental health services – Prepared for the Office of the Chief Psychiatrist* (Report, September 2017) 7.

[84] Webber, Mcvilly, and Chan, 'Restrictive Interventions for People with a Disability Exhibiting Challenging Behaviours: Analysis of a Population Database', Lynne S. Webber et al., 'Factors Associated with the Use of Mechanical Restraint in Disability Services', *Journal of Intellectual & Developmental Disability*, 44/1 (2019), 116-20.

[85] Ibid., p. 84-85. See also: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. 2020. Report on Public hearing 6: Psychotropic medication, behaviour support and behaviours of concern. Retrieved from: https://disability.royalcommission.gov.au/publications/report-public-hearing-6-psychotropic-medication-behaviour-support-and-behaviours-concern

[86] Spivakovsky, Claire., Steele, Linda., and Wadiwel, Dinesh. 2023. Restrictive practices: a pathway to elimination. A research report commissioned by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. University of Melbourne, Australia.

[87] Ibid.

[88] Louise Denne, Nick Gore, Carl Hughes, Sandy Toogood, Edwin Jones & Freddy Jackson Brown, 'Implementing evidence-based practice: The challenge of delivering what works for people with learning disabilities at risk of behaviours that challenge', (2020), vol 25 (3), Tizard Learning Disability Review, p 3; Stella Koritsas & Teresa Iacono, 'Predictors of challenging behaviour in adults with intellectual disability', (2015), vol 9 (6), Advances in Mental Health and Intellectual Disabilities, pp 312-326.

[89] Afia Ali, Jessica Blickwedel & Angela Hassitotis, 'Interventions for challenging behaviour in intellectual disability', (2014), vol 20 (3), Advances in Psychiatric Treatment, p 184; see also Martin Stevens, 'Moral positioning: Service user experiences of challenging behaviour in learning disability services', (2006), vol 36 (6), British Journal of Social Work, pp 955-978

[90] Karl Nunkoosing & Mark Haydon-Laurelut, 'Intellectual disability trouble: Foucault and Goffman on 'challenging behaviour'' in Dan Goodley, Bill Hughes & Lennard Davis (eds) Disability and Social Theory, Palgrave Macmillan, 2012, p 195; Tessa-May Zirnsak, 'Contextualizing distress: Understanding challenging behaviour as a product of resistance in the Intellectual Disability community', (2021), vol 15 (3), Journal of Literary & Cultural Disability Studies, p 269-286.

[91] Elspeth Bradley & Marika Korossy, 'HELP with behaviours that challenge', (2016), vol 22 (2), Journal on Developmental Disabilities, p 101.

---

[92] Daniel Lawrence, Ruth Bagshaw, Daniel Stubbings & Andrew Watt, 'Restrictive practices in adult secure mental health services: A scoping review', vol 21 (1), International Journal of Forensic Mental Health, p 81; Laura Higgins, 'Secure unit: Positive behavioural support and restraint reduction in a unit for offenders with an intellectual disability and/or autism: practice paper', vol 11 (1), International Journal of Positive Behavioural Support, pp 42-54

[93] Paul Ramcharan, Karen Nankervis, Maria Strong & Alan Robertson, 'Experiences of restrictive practices: A view from people with disabilities and family carers: A final research report to the Office of the Senior Practitioner', Research report for Office of the Senior Practitioner, Victorian Government, May 2009, p 11.

[94] Ibid., 35.

[95] Claire Spivakovsky, 'Governing Freedom through Risk: Locating the Group Home in the Archipelago of Confinement and Control' (2017) 19(3) Punishment & Society 374; Lynne Weber, Keith McVilly and Jeffry Chan, 'Restrictive Interventions for People with Intellectual Disability Exhibiting Challenging Behaviours: Analyses of a Population Database' (2011) 24(6) *Journal of Applied Research in Intellectual Disabilities*, pp 495-507.

[96] https://disability.royalcommission.gov.au/publications/restrictive-practices-pathway-elimination

[97] Ibid.

[98] Ibid.

[99] Claire Spivakovsky, 'Governing Freedom through Risk: Locating the Group Home in the Archipelago of Confinement and Control' (2017) 19(3) Punishment & Society 374; Lynne Weber, Keith McVilly and Jeffry Chan, 'Restrictive Interventions for People with Intellectual Disability Exhibiting Challenging Behaviours: Analyses of a Population Database' (2011) 24(6) *Journal of Applied Research in Intellectual Disabilitie*.

[100] Ibid.

[101] Ibid.

[102] Xiao, A. (2026). Australia misses 20-year public transport accessibility target as many train and tram networks fail people with disabilities. *ABC News.* Retrieved from: https://www.abc.net.au/news/2023-01-16/australia-misses-20-year-public-transport-accessibility-target/101858532

[103] Xiao, A. (2026). Australia misses 20-year public transport accessibility target as many train and tram networks fail people with disabilities. *ABC News.* Retrieved from: https://www.abc.net.au/news/2023-01-16/australia-misses-20-year-public-transport-accessibility-target/101858532

[104] Convery, S. (2022). Left behind: the fight for accessible public transport in Victoria. *The Guardian.* Retrieved from: https://www.theguardian.com/australia-news/2022/jun/13/left-behind-the-fight-for-accessible-public-transport-in-victoria;
Dennis, J. (2022). Queensland is unlikely to meet the legislated goal of having all train stations fully accessible this year. *ABC News.* Retrieved from: https://www.abc.net.au/news/2022-03-23/qld-public-transport-disability-access-train/100913440;
Doman, M., Scott, N., and Liu, R. (2018). The 'unconscionable' state of Australia's train stations. *ABC News.* Retrieved from: https://www.abc.net.au/news/2018-08-29/the-unconscionable-state-of-australias-train-stations/10147174

[105] Orr, A. (2023). There's something 'insulting' about this photo. Can you spot it? *SBS News.* Retrieved from: https://www.sbs.com.au/news/article/can-you-spot-what-is-insulting-about-this-photo/h90qxl0b5