



6 September 2024

## **Review of Australia's Disability Strategy (ADS)**

### **Joint submission from Inclusion Australia and Down Syndrome Australia consortium**

We are pleased to provide this joint submission to the Review of Australia's Disability Strategy (ADS) on behalf of Inclusion Australia and the Down Syndrome Australia consortium.

We look forward to continuing to work with the Department of Social Services on ensuring ADS reflects the Recommendations of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Disability Royal Commission).

We warmly invite further conversations on the issues raised in this submission.

## About our organisations

Inclusion Australia is the national peak organisation representing the rights and interests of Australians with an intellectual disability and their families.



Inclusion Australia



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 and territory across Australia:

- ACT Down Syndrome and Intellectual Disability (ACT DSID)
- Council for Intellectual Disability (NSW)
- Developmental Disability WA (DDWA)
- Inclusion Northern Territory (Inclusion NT)
- Parent to Parent (P2P, Queensland)
- South Australian Council on Intellectual Disability (SACID)
- Speak Out Advocacy (Tasmania)
- Victorian Advocacy League for Individuals with Disability (VALID).

Down Syndrome Australia was established in 2011 as the peak body for people with Down syndrome in Australia.

Our purpose is to influence social and policy change and provide a national profile and voice for people living with

Down syndrome. Our vision is an Australia where people living with Down syndrome are valued, reach their potential, and enjoy social and economic inclusion.



Down Syndrome  
Australia

DSA leads a consortium of organisations to represent people with Down syndrome and similar chromosomal variations. The Consortium provides systemic advocacy for Australians with Down syndrome and similar chromosomal variations.

## Feedback and recommendations

Our organisations were heavily involved with 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 an inclusive Australia. ADS is central to this, and it is crucial that it reflects the Recommendations of the Disability Royal Commission and supports its implementation.

The feedback below also contains input from Inclusion Australia's Policy Officers with an intellectual disability.

### Implementation mechanisms

ADS currently does not contain clear or ambitious targets across a number of its Outcome Areas. In part, this should be addressed by the Disability Royal Commission's Recommendation to strengthen the ADS Data Improvement Plan (Recommendations 5.2 and 12.7).

We believe implementing ADS requires the following:

- Meaningful inclusion of people with an intellectual disability in the governance, collection and interpretation of reporting and monitoring mechanisms.
- Clear and ambitious targets need to be set in relation to current baselines, so there are clear benchmarks to measure progress in different Outcome Areas.
- Evidence for good practices in international contexts should be considered, so approaches with a strong evidence base can be replicated locally.

### Economic and financial security

Australia has one of the lowest employment participation rates for people with disability in the OECD.<sup>1</sup> 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).<sup>2</sup>

As well as aligning with Disability Royal Commission Recommendations, ADS should take action to improve employment outcomes and financial security by implementing the following:

- Promote the establishment of specific and disaggregated targets for disability employment in the public sector—with specific targets for people with an intellectual disability—and for new public service hires in government agencies and departments, as per Disability Royal Commission Recommendations 7.18, 7.19 and 7.22.
- Encourage the active, visible presence and leadership of people with disability including people with an intellectual disability, within the public sector workforce to model and grow employment for people with disability, including the establishment of specific and ambitious targets.
- Ensure all levels of government to play an active role in opening employment to people with an intellectual disability and providing and modelling the right support.
- Promote [evidence-based practices](#) to support people with an intellectual disability in gaining and sustaining employment in the open workforce.
- Improve access to independent, accessible information and decision-making support to people with an intellectual disability and families, with a focus on young people during the transition from school to work.

Inclusion Australia’s Policy Officers with an intellectual disability also said:

*ADS needs it make it clear that all people with a disability should be able to work if they want to. Make sure there is accessible information before they apply for a job so people know what options are out there. The government needs to support people with disability to gain the experiences and support to work by doing on-the-job training.*

## **Inclusive homes and communities**

Fully inclusive living is possible for people with an intellectual disability, including people with high support needs. The Disability Royal Commission heard about several innovative housing models that are already progressing in Australia.<sup>3</sup>

To improve outcomes in this area, ADS should:

- Promote investment in and evaluation of alternative housing models, including collecting evidence from international contexts.
- Support the development of clear and supportive transition pathways (such as moving out of the family home, or out of a group home) that provide access to independent information, advocacy and support for people with an intellectual disability to explore and make decisions about their housing options.

- Promote ongoing, extensive and independent evaluation and dissemination of emerging best practice in home and living supports, as referred to in Disability Royal Commission Recommendation 7.42.
- Undertake a cost-benefit analysis of shared home and living supports to discern the true cost associated with congregate housing arrangements like group homes. This should take into account the costs incurred to governments, communities and families as a result of violence, abuse, neglect and exploitation that is disproportionately experienced in segregated settings.<sup>4</sup>

Inclusion Australia's Policy Officers with an intellectual disability also said:

*ADS should be focusing on making sure there is accessible information on options for where to live, like Easy Read, so people with an intellectual disability can understand and choose where they want to live and who they want to live with.*

## Safety, rights and justice

### Violence against women and girls

The rates for violence against women and girls with disability, particularly intellectual disability, are extremely high. For people with an intellectual disability who also experience other social intersections, the statistics are especially alarming.<sup>5</sup> There is little evidence that there is recent change to these rates based on the interventions and supports that are currently occurring and there is no known significant nationwide action to improve safety.

Significantly, frontline services who respond to instances of domestic and family violence or sexual violence are not receiving the appropriate specialist training or resources, including funding, to respond in urgent and crisis situations. This need for appropriate specialist training and resources extends to first responders, such as police, ambulance and medical services.

In order to respond to this issue, ADS should:

- Promote the collection and report on data for people with disability, including people with intellectual disability, accessing purpose-specific services for reporting and requesting support on all aspects of violence.
- Implement Recommendation 8.20 of the Disability Royal Commission, to improve police responses to people with a disability and introduce an alternative reporting pathway for people with disability to report crimes to police.
- Incorporate the National Adult Safeguarding Framework, per Recommendation 11.1.
- Implement nationally consistent Community Visitor Schemes, per Recommendation 11.12

- Review and determine appropriate funding levels for frontline crisis response services.

### **The use and impact of restrictive practices**

While the use of restrictive practices has not historically been within the remit of ADS, the findings of the Disability Royal Commission demonstrate the need for greater coordination and collaboration to reduce and eliminate the use of restrictive practices in Australia.

The Disability Royal Commission showed that people with an intellectual disability, especially people with high support needs, are among the most likely to experience restrictive practices, especially chemical restraint.<sup>6</sup>

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. People in prison and youth detainees with disability, particularly with an intellectual disability, are disproportionately secluded in solitary confinement for long periods of time.<sup>7</sup>

We believe that this evidence—which was explored across a number of [Public hearings](#), [research reports](#) and [issues papers](#)—demonstrates the need for targeted strategies that work to address the pathologisation of so-called ‘behaviours of concern’ and the ways this incentivises the use, and in many cases over-use,<sup>8</sup> of restrictive practices—particularly for people with complex needs.

This is also closely related to community attitudes, where ‘behaviours of concern’ reflect dominant social attitudes by requiring someone else to interpret it as “dangerous, frightening, distressing or annoying”.<sup>9</sup> This can lead to the ‘criminalisation of disability’, which the Disability Royal Commission heard about across several of its hearings.<sup>10</sup> This contributes significantly to the overrepresentation of people with disability—especially people with cognitive disabilities—in the criminal justice system.<sup>11</sup>

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.

As such, we believe ADS is well-positioned to:

- Ensure the reduction and elimination of restrictive practices is included in the ‘safety, rights and justice’ Outcome Area and TAP.
- Work with the sector to devise targeted actions that will promote coordination across jurisdictions.
- Promote and 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.

- Work with states and territories, and the disability community and advocacy sector, to improve access to behaviour support practitioners.

## **Personal and community support**

There should be a focus on building informal supports and natural safeguards in ADS to strengthen the ‘disability ecosystem’ discussed in the Discussion Paper. This needs to 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.

These are all part of factors that make an inclusive life—connection, relationships, having a job, and being part of community. Evidence shows that these are some of the strongest safeguards against abuse.<sup>12</sup>

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 about the lack of specific recommendations about building informal supports in the lives of people with an intellectual disability. This is especially those who experience the greatest barriers to inclusion, including people living in group homes or other closed settings such as boarding houses, prisons or hospitals.

We believe ADS is well-positioned to strengthen the informal supports listed above. To do this, we recommend the following actions be included in the ‘Personal and community support’ Outcome Area of ADS.

### **Supported decision-making**

ADS should include supported decision-making as one of its key policy priorities. It should promote greater access to supported decision-making across all aspects of Australian society by:

- Promoting a significant investment in targeted programs which increase the understanding and skills of decision-makers and their trusted, informal supporters.

- Ensure people with communication support needs receive ongoing capacity building to develop the skills of their paid and informal support people in recognising, understanding and supporting the continued development of the person’s expressive communication to achieve supported decision-making.
- Establish a standard for best practice in supported decision-making using the supported decision-making principles listed in Recommendation 6.6 of the Disability Royal Commission.
- Support the implementation of Recommendations 6.6, 6.7, 6.13, and 6.14 in relation to 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.

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.

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.

In view of this, we recommend ADS implement the following:

- Improve data collection and reporting on met and unmet demand for disability advocacy, per Recommendation 6.22 of the Disability Royal Commission.
- Determine the full cost of advocacy service delivery in partnership with the disability advocacy sector, including recipients of those services.
- Align with Recommendation 6.21 of the Disability Royal Commission to bolster funding for the advocacy sector and prevent precarity and insecurity.

## **Education and learning**

Recommendations in support of inclusive education were a significant aspect of the Disability Royal Commission and it was disappointing that that the Commonwealth



Government did not actively engage with or support the recommendations. Generational change in the education systems will require vision and leadership at the Commonwealth level, utilising levers to encourage consistency and momentum at the State and Territory level.

Responding to those recommendations where the Government response indicated 'support in principle' could be reported on under ADS arrangements and particularly through the governance arrangements of the ADS. If inclusive education is not a priority, there will be little movement towards meeting Australia's international obligations on inclusive education.

To support this generational movement towards inclusive education, ADS should:

- Prepare or update a TAP for inclusive education, which prioritises the development of a National Roadmap to Inclusive Education, per Recommendation 7.13 of the Disability Royal Commission.
- Implement Recommendations 7.2, 7.3, 7.7, 7.8, 7.9, 7.10 and 7.12 of the Disability Royal Commission.
- Undertake work on community attitudes toward inclusion in education systems for people with disability.

## **Health and wellbeing**

The Disability Royal Commission 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.

Importantly, the Disability Royal Commission's 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.

We believe ADS should work collaboratively with the Centre to ensure its policy priorities are aligned. ADS can also support increased access to good quality, accessible health services through the following recommendations:

- Improve and implement the 'intellectual disability health capability framework', which will be foundational for further codesign work if other groups (beyond people

with an intellectual disability) were to be included 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.

## **Community attitudes**

We strongly believe the new Community Attitudes TAP must be meaningfully connected to policy priorities in other Outcome Areas, given the influence of community attitudes on so many of the poorer life outcomes many people with an intellectual disability experience.

For example, evidence is clear that negative attitudes among employers and low expectations of people with disability are some of the biggest barriers to inclusive employment.<sup>13</sup> To address those barriers and change negative community attitudes, the active, visible presence and leadership of people with an intellectual disability is essential.<sup>14</sup>

In addition, research continues to highlight direct, personal contact between people with and without an intellectual disability as a crucial catalyst for positive attitude-change.<sup>15</sup>

Evidence also suggests that the quality—as well as the frequency—of contact with people with an intellectual disability is an important determining factor in the development of positive attitudes,<sup>16</sup> which especially thrives in inclusive education settings among children and young people.<sup>17</sup>

Likewise, one of the major causes of lack of personal contact between people with and without an intellectual disability is segregated schooling. While people with an intellectual disability are made invisible to their peers in such settings, 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.

As such, one of the most decisive actions to improve community attitudes is inclusive education—noting our earlier comments in relation to the Education and Learning Outcome Area of ADS.

We strongly recommend ADS:

- Engage meaningfully with people with an intellectual disability when devising the actions under the Community Attitudes TAP, especially as they relate to employment and education.
- Ensure the Community attitudes TAP is genuinely connected to other Outcome Areas. This recognises the particular impact of community attitudes on several of the Outcome Areas, especially employment and education.

## Reference list

- <sup>1</sup> 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; Inclusion Australia. 2023. Equal Pay Equal Rights--Final submission to the Disability Royal Commission. Retrieved from: <https://www.inclusionaustralia.org.au/submission/equal-pay-equal-rights/>
- <sup>2</sup> 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.
- <sup>3</sup> 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.
- <sup>4</sup> 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.
- <sup>5</sup> <https://disability.royalcommission.gov.au/public-hearings/public-hearing-17>
- <sup>6</sup> 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>
- <sup>7</sup> 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 Jeffrey 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.
- <sup>8</sup> Ibid.
- <sup>9</sup> 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
- <sup>10</sup> Disability Royal Commission. 2020. Overview of responses to the Criminal justice system Issues paper. Retrieved from: <https://disability.royalcommission.gov.au/publications/criminal-justice-system>
- <sup>11</sup> Disability Royal Commission. 2021. Public hearing 11: The experiences of people with cognitive disability in the criminal justice system. Retrieved from: <https://disability.royalcommission.gov.au/public-hearings/public-hearing-11>
- <sup>12</sup> 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.
- <sup>13</sup> 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; Inclusion Australia. 2023. Equal Pay Equal Rights--Final submission to the Disability Royal Commission. Retrieved from: <https://www.inclusionaustralia.org.au/submission/equal-pay-equal-rights/>
- <sup>14</sup> Idle, J., Giuntoli, G., Fisher, KR, Robinson, S., Purcal, C., Newman, C., Reedy, K. (2022). Research Report – Changing community attitudes to improve inclusion of people with disability. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Retrieved from: <https://disability.royalcommission.gov.au/publications/research-report-changing-community-attitudes-improve-inclusion-people-disability>. Page 53-57.
- <sup>15</sup> Scior, K. (2011). Public awareness, attitudes and beliefs regarding intellectual disability: A systematic review.

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Research in Developmental Disabilities, 32(6), 2164–2182;

Seewooruttun, L. & Scior, K. (2014). Interventions aimed at increasing knowledge and improving attitudes towards people with intellectual disabilities among lay people. *Research in Developmental Disabilities*, 35(12), 3482–3495.;

Walker, J. & Scior, K. (2013). Tackling stigma associated with intellectual disability among the general public: A study of two indirect contact interventions. *Research in Developmental Disabilities*, 34(7), 2200–2210

<sup>16</sup> Page, S. L. & Islam, M. R. (2015). The role of personality variables in predicting attitudes toward people with intellectual disability: An Australian perspective. *Journal of Intellectual Disability Research*, 59(8), 741–745.

<sup>17</sup> 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.;

Shields, N., Bhowon, Y., Prendergast, L., Cleary, S., & Taylor, N. F. (2023). Fostering positive attitudes towards interacting with young people with disability among health students: a stepped-wedge trial. *Disability and Rehabilitation*, 46(6), 1212–1219. <https://doi.org/10.1080/09638288.2023.2193429>