



Inclusion Australia

Submission to the Department of Social Services: Developing the National Autism Strategy

30 October 2023

Contents

Introduction	3
Summary of recommendations	6
Recommendations and feedback	7
1. Genuinely engage with autistic people with an intellectual disability and their families	7
2. Engage with autistic people in closed settings	9
3. Align the Strategy with other policy reforms and initiatives	11
4. Ensure better support for autistic people interacting with the justice system	13
5. Include a focus on positive behaviour support and reducing restrictive practices	16
6. Address mental health barriers faced by autistic people with an intellectual disability	18
7. Include supported decision making and support the development of natural safeguards	19

Introduction

Inclusion Australia is the national Disability Representative Organisation (DRO) representing the rights and interests of Australians with an intellectual disability and their families. Founded in 1954, our mission is to work to make sure people with an intellectual disability have the same opportunities as people without disability. Inclusion Australia's strength comes from our state members who use their combined experience and expertise to promote the inclusion of people with an intellectual disability.

Our state members are:

- Developmental Disability Western Australia (DDWA) – Western Australia
- NSW Council for Intellectual Disability (CID) – New South Wales
- Parent to Parent (P2P) – Queensland
- South Australian Council on Intellectual Disability (SACID) – South Australia
- Speak Out Advocacy – Tasmania
- Victorian Advocacy League for Individuals with Disability (VALID) – Victoria.

Since September 2021 we have had a Northern Territory team based in Darwin. Our work in the Northern Territory is informed by a Local Steering Group that includes representatives from advocacy and other territory-based organisations.

We thank the Department of Social Services for the opportunity to provide feedback to its Discussion Paper and to contribute to the development of the National Autism Strategy.

We are grateful to have been involved with the development of the Strategy at different stages of its design, including being engaged by the Department earlier this year to provide a research report on key issues facing autistic people with an intellectual disability, and several proposed principles to guide the Strategy consultation processes.¹

A key aim of this work was to elevate the experience and expertise of people with some of the most complex support needs, their families, and supporters.

Because of a range of systemic barriers, entrenched disadvantage and exclusion, the experiences and needs of this group are underrepresented in government policy. As the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability has unequivocally shown, this cohort often experiences poorer outcomes in and exclusion from social and economic life,² as well as in the areas of diagnosis, services and supports; health and mental health; and the justice system.³

¹ Inclusion Australia, 2023. 'Engaging with autistic people with an intellectual disability'.

<https://www.inclusionaustralia.org.au/submission/engaging-with-autistic-people-with-an-intellectual-disability/>

² Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. 2023. *Executive Summary: Our vision for an inclusive Australia and Recommendations*. Page 82.

<https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Executive%20Summary%2C%20Our%20vision%20for%20an%20inclusive%20Australia%20and%20Recommendations.pdf>

³ Ibid.

Some of these aspects are mentioned in the Discussion Paper, but many are not—especially the particularities of the experiences of people with complex needs, which was a key focus of our research report earlier this year.

While the Discussion Paper shows a range of important evidence revealing a path towards a holistic Strategy, we are concerned that there remain some significant gaps which, if not addressed, will impede its efficacy and exclude many autistic people with an intellectual disability and their families. We received feedback earlier this year from our community that families and people with complex support needs were not feeling adequately included or considered through the consultation process.

From our perspective, we are now at a critical point in the consultation process—the lead-up to the publication of the draft Strategy—and the Department must ensure that this group has been meaningfully consulted with and included in the Strategy.

We believe a lack of meaningful engagement, representation, and resourced solutions to meet the needs of people with complex needs will also impact the efficacy of the Strategy for other autistic Australians.

As we discuss in our recommendations, Autistic people with an intellectual disability are very likely to experience segregated settings in housing, work, and social life. Many within this cohort are likely to be residing in closed settings such as group homes, hospitals, or prisons.

Within these settings, we know that there are increased instances of restrictive practices, which very often result in severe human rights breaches.⁴

We know there is less access to important safeguards to protect people’s human rights and ensure quality of service provision, such as supported decision making; transparent and accessible reporting systems and oversight; evidence-based behaviour support; and access to individual advocacy.⁵

We know that people within this cohort are overwhelmingly more likely to rely on income support payments as their primary income, do not have access to choices about where they work, and that this means many live in entrenched poverty.⁶

We know that in closed settings like group homes, and specifically amongst this cohort of people with complex needs, there are increased levels of mental ill-health, as well as lower prevention and early detection rates, and diagnostic overshadowing, which in turn prevents people from accessing

⁴ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. 2023. *Executive Summary: Our vision for an inclusive Australia and Recommendations*. Page 82. <https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Executive%20Summary%2C%20Our%20vision%20for%20an%20inclusive%20Australia%20and%20Recommendations.pdf>

⁵ Ibid.

⁶ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2023. *The association between segregated education and employment on the outcomes of NDIS participants*. Prepared by the Royal Commission’s Data and Analytics Team. <https://disability.royalcommission.gov.au/system/files/2023-09/Research%20Report%20-%20The%20association%20between%20segregated%20education%20and%20employment%20on%20the%20outcomes%20of%20NDIS%20participants.pdf>

potentially life-saving mental health support,⁷ as well as efficacious and human rights-based behaviour support.

In our feedback below, we emphasise that it is crucial the consultation process currently underway engages with people in these settings, their families and other supporters, to meaningfully include those perspectives with targeted, cross-policy, and appropriately resourced solutions within the Strategy.

There is also, largely due to the findings of the Disability Royal Commission, much evidence (which will be cited below) of the structural barriers that prevent people—especially people with very complex support needs—from living an inclusive life, as well as a growing evidence base for critical policy interventions to overcome them. This evidence must be critically examined by the Department and form the basis for the Strategy’s actions to create meaningful change across systems: from education, employment, justice, housing and health.

We urge the Department to engage with those who have been historically, and in many cases are still, excluded from meaningful consultation and co-design of solutions. It is our hope and conviction that through genuine engagement with those most marginalised and underrepresented—including their families and supporters—the Strategy will be appropriately targeted and inclusive, and have a genuine impact for not only this cohort, but on all autistic Australians.

⁷ 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

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;

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.

Summary of recommendations

1. Genuinely engage with autistic people with an intellectual disability and their families

The national consultation process, and the Strategy itself, must provide evidence it has engaged meaningfully with autistic people with an intellectual disability and their families or supporters.

2. Engage with autistic people in closed settings

The consultation process and the Strategy itself must engage with and include evidence-based strategies to target the needs of those who are residing in closed settings such as group homes, prisons or hospitals.

3. Align the Strategy with other policy reforms and initiatives

The Strategy must meaningfully align with, and build on, other important cross-policy areas and be sufficiently resourced to deliver broad systemic change alongside other policy developments.

4. Ensure better support for autistic people interacting with the justice system

The Strategy must engage with the experiences of autistic people with an intellectual disability in the context of the justice system and put forward targeted strategies to increase peoples' access to necessary supports when navigating the justice system.

5. Include a focus on positive behaviour support and reducing restrictive practices

The Strategy must include an evidence-based understanding of restrictive practices and behaviour support and shape its subsequent actions based on lived experience.

6. Address mental health barriers faced by autistic people with an intellectual disability

The Strategy must include targeted and sustainably funded actions to address mental health barriers experienced by autistic people with an intellectual disability, especially in relation to diagnostic overshadowing.

7. Include supported decision-making and support the development of natural safeguards

The Strategy must include targeted actions and significant investment in independent resources for capacity building to increase social and economic inclusion as well as natural safeguards in the lives of autistic people with an intellectual disability, especially access to supported decision-making.

Recommendations and feedback

1. Genuinely engage with autistic people with an intellectual disability and their families

The national consultation process, and the Strategy itself, must provide evidence it has engaged meaningfully with autistic people with an intellectual disability and their families or supporters.

As we have outlined in our recent research report for the Department,⁸ people with a dual diagnosis of autism and intellectual disability experience the world in a very different way to people with autism or intellectual disability diagnoses alone.

Having a dual diagnosis, where that duality is not recognised or appropriately supported, can have compounding disabling impacts. This often means autistic people with an intellectual disability have higher support needs than people with autism or intellectual disability alone.

In many ways, the barriers to an inclusive life faced by this cohort are also more acute and difficult for individuals and families to overcome. There is a growing body of evidence to demonstrate this.

Autistic people with an intellectual disability may have very different experiences based on the order in which they received their diagnoses, and the supports they have or have not been given for each disability. We have heard that a diagnosis for both disabilities for the same person can be difficult to get, as diagnosticians have been known to choose not to perform additional diagnoses due to “not wanting to add labels” or a sense that “one diagnosis is enough”.⁹

Because of a range of entrenched, systemic barriers in the policy landscapes of education, housing, employment—as well as the historic legacies of segregation, institutionalisation, and the systematic denial of the human rights of people with disability—the needs of this group are overwhelmingly underrepresented and unaddressed in government policy.

As such, understanding the compounding impacts and multifaced experiences of this community is a crucial foundation for the Department in the national consultation process, and in developing a national Strategy that can meet needs of this cohort and ensure their voices are included.

Our concern is that if the Strategy development process does not engage with this cohort (including their family members and supporters) in the settings in which this cohort is likely to live and work in (see recommendation 2), the actions put forward by the Strategy will not be sufficiently targeted, and the Strategy will therefore fail to implement properly resourced, evidence-based solutions for

⁸ Inclusion Australia, 2023. ‘Engaging with autistic people with an intellectual disability’.

<https://www.inclusionaustralia.org.au/submission/engaging-with-autistic-people-with-an-intellectual-disability/>

⁹ Allison, C., Auyeung, B., & Baron-Cohen, S. (2012). Toward brief “Red Flags” for autism screening: the Short Autism Spectrum quotient and the Short Quantitative Checklist for autism in toddlers. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51(2), 202-2012. <https://doi.10.1016/j.jaac.2011.11.003>;

Metcalfe, D., McKenzie, K., McCarty, K., & Murray, G. (2020). Screening tools for autism spectrum disorder, used with people with an intellectual disability: A systematic review. *Research in Autism Spectrum Disorders*, 74, 101549–. <https://doi.org/10.1016/j.rasd.2020.101549>

autistic people with an intellectual disability. We believe this will also impact the efficacy of the Strategy for other autistic Australians.

As with all other groups, autistic people with an intellectual disability are the experts in their own experiences.

Yet, as we have previously highlighted, families of people with complex needs have told us that so far it feels like the National Autism Strategy work is focused on, and led by, autistic people who do not have intellectual disability or complex communication or support needs. Many of the families we spoke to said they do not feel their experiences are being represented within the Strategy or the Oversight Council. This includes experiences more commonly experienced by autistic people with an intellectual disability such as complex support needs and plans, non-speaking communication supports and styles, and abuse and neglect by service providers, post-traumatic stress disorder, and interactions with the justice system.

In our research report to the Department in June this year, we suggested the following actions. In this submission, we seek to re-emphasise these recommendations and urge the Department to implement them. These are also expanded upon in recommendation 2.

- Put specific engagement structures in place within the Phase 2 of the development of the Strategy, to connect with this cohort. This means including consultations and measures that acknowledge the specific experiences and needs of this group, including specific data collection questions and measures that reflect these experiences.
- Consider autistic people with an intellectual disability and parents as paid consultants to fill Oversight Council and Working Group experience and/or representation gaps.
- Consider including subgroups within the existing National Autism Strategy working groups to reflect specific issues faced by autistic people with an intellectual disability. These could include a subgroup on behaviour supports or restrictive practices, justice system interactions, and service provider complaints and escalation. It is our belief that these issues should be specifically included in the Strategy and not segregated into a separate working group. These issues should be treated as relevant to all autistic people, not just those who also have intellectual disability.

2. Engage with autistic people in closed settings

The consultation process and the Strategy itself must engage with and include evidence-based strategies to target the needs of those who are residing in closed settings such as group homes, prisons or hospitals.

People with autism and an intellectual disability are likely to be residing in restricted environments, like group homes or hospitals, and they are overrepresented in interactions with the criminal justice system.¹⁰ For many, those experiences are likely to have been traumatic.

Additionally, we hear that many autistic people with an intellectual disability and their families often face barriers like discrimination, insufficient understanding of their needs, and exclusion through their engagement in other services, including disability services, health, and education. This has often happened in multiple ways over many years.

As a result, for many autistic people with an intellectual disability—and especially those within the cohort mentioned above, there is a “deep sense of mistrust” of government systems, particularly the NDIS.

As the Disability Royal Commission has found, certain experiences of violence, abuse, neglect, and exploitation affect people with certain disability types more than others, and very often this is because of the increased likelihood that that cohort is more likely to reside in a segregated setting, separate from the community.

While it is not presently possible to say specifically the number of autistic people with an intellectual disability for whom this is a reality due to a significant paucity of data, the findings of the Disability Royal Commission have clearly shown that people with cognitive impairment:¹¹

- Experience higher rates of violence and abuse¹²
- Are more likely to be living in a group home¹³
- Have less access to quality healthcare and are likely to be subject to systemic neglect in the health system.¹⁴

¹⁰ 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. <https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Executive%20Summary%2C%20Our%20vision%20for%20an%20inclusive%20Australia%20and%20Recommendations.pdf>

¹¹ ‘Cognitive impairment’ is the term used by the Disability Royal Commission in its Final Report. It is an umbrella term that describes the effects of several conditions, including intellectual disability. In public hearings and evidence in which the experiences of people with cognitive impairment are described, very often those people have an intellectual disability and also have very high support needs and/or complex communication needs. As such, we can discern that the prevalence of poorer outcomes associated with people with cognitive impairment very often relates to those with the most complex needs, which includes autistic people with an intellectual disability.

¹² Ibid., p. 84-85.

¹³ Ibid., p. 46-47.

¹⁴ 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. <https://disability.royalcommission.gov.au/system/files/2020-10/Report%20-%20Public%20hearing%204%20-%20Healthcare%20for%20people%20with%20cognitive%20disability.pdf>. Further, Prof Nicholas Lennox from the Queensland Centre for Intellectual and Developmental Disabilities gave evidence in Public Hearing 4 on the devaluing of the lives of people with intellectual disability. He said this devaluing occurs ‘across the Australian community and is reflected in our health care system and those who work in this system’.

- Are more likely to be overprescribed psychotropic medications. In some cases the number and dosage levels of such medications administered to people with cognitive disability are so significant, this constitutes abuse¹⁵
- Experience more instances of restrictive practices, especially chemical restraint,¹⁶ often as a service response to ‘behaviours of concern’ (which can lead to more behaviours of concern)¹⁷
- Are overrepresented in the criminal justice system¹⁸
- If found unfit to stand trial (for example, because the person does not understand the proceedings or charges against them, or do not have access to the appropriate supports) may be detained for longer periods than had they been found guilty and sentenced accordingly, and are at risk of being detained indefinitely¹⁹
- Experience a greater prevalence of seclusion and solitary confinement in prisons²⁰
- Have less access to justice as victims of crime.²¹

Unequivocal evidence provided by the Disability Royal Commission demonstrates the need for the Strategy to include and engage with those who are far more likely to experience these settings (especially group homes, prisons, and hospitals) which are associated with the most severe human rights breaches.

As the Discussion Paper rightly underscored, listening carefully to the community is an important step to deciding what goes in the Strategy. **Listening to those who are the hardest to reach due to the oppressive systemic realities that affect certain cohorts more than others is essential to ensure the policy directives that flow from the Strategy have an impact.**

Further, as we have highlighted in our previous research report, consultations to develop the Strategy must recognise the trauma that many people have been through because of their experiences in such settings, and seek to engage in a safe, person-centred, and trauma-informed manner.²²

¹⁵ 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.

<https://disability.royalcommission.gov.au/publications/report-public-hearing-6-psychotropic-medication-behaviour-support-and-behaviours-concern>

¹⁶ Ibid., p. 82.

¹⁷ Ibid., p. 81-83.

¹⁸ 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.

<https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Executive%20Summary%2C%20Our%20vision%20for%20an%20inclusive%20Australia%20and%20Recommendations.pdf>

¹⁹ Ibid., p. 129.

²⁰ Ibid., p. 124-125.

²¹ Ibid.

²² See, for example, guidance by the Blue Knot Foundation: <https://professionals.blueknot.org.au/>.

3. Align the Strategy with other policy reforms and initiatives

The Strategy must meaningfully align with, and builds on, other important cross-policy areas and be sufficiently resourced to deliver broad systemic change alongside other policy developments.

The four key themes outlined by the Discussion Paper identify important issues and a range of related evidence about what the Department has heard from the community so far. This is a promising starting point, and we strongly endorse these findings.

Going forward, we recommend the Department ensures the Strategy is mutually aligned with and builds on other policy initiatives and forthcoming legislative actions and is sufficiently resourced to deliver broad systemic change.

This includes:

- The recommendations of the Disability Royal Commission, and especially the federal government's forthcoming response
- Australia's Disability Strategy and its Targeted Action Plans
- Employ My Ability, the national Disability Employment Strategy
- The National Roadmap for Improving the Health of People with Intellectual Disability
- The National Framework for Protecting Australia's Children 2021-2031
- The National Plan to End Violence against Women and Children 2022-2032.

There are other important systemic considerations the Strategy must meaningfully address and be aligned with so it can bring about real, lasting change.

For example, the consultation process has heard about many of the key barriers to economic inclusion for autistic people. In developing the draft Strategy, any actions put forward must interact with and seek to implement broader systemic change. One critical example is reform to the Disability Support Pension (DSP) and related income support systems.

The DSP is a crucial income support payment for many people with disability, especially people with an intellectual disability. It is currently difficult to know how many people in this group are also autistic, but it can be discerned that people with this dual diagnosis are very likely to be DSP recipients. For example, young people with an intellectual or learning disability are nearly half of all DSP recipients. Yet for people with an intellectual disability—a lifelong, permanent condition—eligibility requirements to get the DSP are unnecessarily repetitive, difficult, and costly. Our community tells us that the DSP and related Services Australia systems are inaccessible and emotionally stressful to navigate.

The DSP system also shuts people out of getting jobs in open employment: 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 following two years.

According to the Australian Institute of Health and Welfare, 71% of people with an intellectual disability—and we could discern, for people with both autism and intellectual disability, especially since both autistic people and people with an intellectual disability are among the least likely to have a job in open employment²³—the DSP is their primary source of income.²⁴ The maximum basic rate for the DSP is \$501.25 per week. We know that this is grossly inadequate.

When people who receive the DSP earn an income, the amount of DSP they receive reduces by 50c for every dollar earned over \$204 each fortnight (known as the taper rate).

While a person receiving the DSP may still be better off working and receiving less DSP, the taper rate and the threshold act as a significant disincentive to work, and many people fear their DSP being taken away if they work in open employment as opposed to, for example, an Australian Disability Enterprise where they will earn far below the minimum wage.

The DSP system needs urgent reform. We have offered specific reform proposals around the DSP and the employment system in other submissions and reports, including through the Disability Employment Services (DES)²⁵ and supported employment reform processes.²⁶ We strongly urge the Department to consider these recommendations so that genuine economic inclusion can occur for all autistic Australians including those with an intellectual disability and complex support needs.

This is one of several associated reforms that the Strategy must engage with and set a mandate to achieve. The following recommendations (4-7) are also made in this vein.

²³ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2023. *The association between segregated education and employment on the outcomes of NDIS participants*. Prepared by the Royal Commission's Data and Analytics Team. <https://disability.royalcommission.gov.au/system/files/2023-09/Research%20Report%20-%20The%20association%20between%20segregated%20education%20and%20employment%20on%20the%20outcomes%20of%20NDIS%20participants.pdf>

²⁴ Australian Institute of Health and Welfare. 2023. 'Disability Support Pension'. <https://www.aihw.gov.au/reports/australias-welfare/disability-support-pension>

²⁵ DES Quality Framework submission, March 2023: <https://www.inclusionaustralia.org.au/submission/disability-employment-services-quality-framework/>; *Making DES work for people with an intellectual disability* report, February 2022: <https://www.inclusionaustralia.org.au/submission/what-works/>; DES reform submission, February 2022: <https://www.inclusionaustralia.org.au/submission/disability-employment-system-reform-submission/>.

²⁶ *Equal Pay, Equal Rights*, our submission to the Disability Royal Commission on inclusive employment for people with an intellectual disability in December 2022: <https://www.inclusionaustralia.org.au/submission/equal-pay-equal-rights/>.

4. Ensure better support for autistic people interacting with the justice system

The Strategy must engage with the experiences of autistic people with an intellectual disability in the context of the justice system and put forward targeted strategies to increase peoples' access to necessary supports when navigating the justice system.

As we highlight in recommendation 1, it is well known that people with complex needs are overrepresented in the criminal justice system. The Discussion Paper also shows what the Department has heard already in this regard.

It is therefore imperative that the consultation process include meaningful consultation with autistic people who have lived experience of prison and other areas of the criminal justice system so that the Strategy is informed by lived experience and includes relevant actions.

We also recommend the Strategy critically evaluates the following existing barriers that autistic people with an intellectual disability are likely to experience in the criminal justice system, listed below, and include specific and fully resourced strategies to address them:

- The criminal justice system does not have mechanisms in place to identify whether autistic people with an intellectual disability require reasonable accommodation in matters—such as additional support for communication
- The justice system does not adequately take into account the additional barriers faced by Aboriginal and Torres Strait Islander people with a dual diagnosis of autism and intellectual disability
- The justice system does not adequately train personnel, and the justice system workforce often does not know how to communicate clearly with people with complex needs and, as a consequence, often responds in an adversarial way to behaviour that is related to disability, trauma or dysregulation
- The justice system does not adequately resource support services for people with complex needs
- Violence and abuse are widespread within the criminal justice system
- The justice system does not adequately prepare people with disability who are incarcerated for a transition back into the community.

In our advocacy over recent years, we have put forward the following recommendations, which relate to the experiences of people with an intellectual disability within the justice system in general, but also apply to autistic people with an intellectual disability.

If included and appropriately funded through the Strategy, we believe these recommendations would contribute to meaningful change for autistic people with an intellectual disability who are in contact with the justice system:

- Incorporate UN Convention rights into all services, policies and programs that apply to people with disability
- Bring all anti-discrimination laws into line with all articles of the UNCRPD

- Develop strong human rights legislation that can be used independently of other legislation and establishes statutory complaints bodies
- Establish statutory safeguarding and complaints mechanisms that are adequately funded to provide inspections and face-to-face visits to all people with intellectual disability in places of detention, incarceration and forced treatment
- Review all protocols and procedures in the criminal justice system to ensure they are universally accessible. Identify and remove all barriers to a fair trial, liberty, legal capacity, and recognition before the law for persons with cognitive disabilities
- Ask the Standing Committee of Attorneys General to dismantle the laws governing the indefinite detention without trial of people with disability
- Annually report on the number of people with disability held on indefinite detention
- Ensure that accessible communication such as Easy Read, plain English, and video is a required form of communication throughout the criminal justice system
- Work with state/territory governments and the NDIA to develop and implement a provider-of-last-resort policy that holds state governments responsible for ensuring the continuation of services for most complex people involved in the criminal justice system when all other forms of service have failed.²⁷

Further, the Strategy should also consider the reality that some autistic people with an intellectual disability who have been victims of crime and have reported abuse and named the perpetrator, have not been able to receive justice. This is often because their witness statement was not accepted due to their intellectual disability, or their communication or other support needs were not met. At times, especially when (i) a reportable incident or crime has occurred in a service, (ii) the perpetrator was the only person on shift, and (iii) there were no witnesses without disability, the police are not able to even get the case to be heard. These are complex systemic challenges that the Strategy must consider.

As a final point, the Disability Royal Commission’s final report details several important findings and related recommendations regarding ending indefinite detention—given the evidence the Commission heard of people with cognitive disability who face serious criminal charges may be found ‘unfit to be tried’.

Each state and territory has its own regime to determine the issue of fitness to be tried and the consequences of a finding that an accused is not fit to be tried. Those regimes are intended to protect people with disability, but in practice, they have been found to deny people with disability the right to exercise legal capacity and can expose them to long-term or indefinite detention.

Prolonged detention places people at risk of violence, abuse, and neglect and experiencing cumulative trauma.

²⁷ Inclusion Australia. 2021. Submission to the DRC on the Criminal Justice System. <https://www.inclusionaustralia.org.au/submission/submission-to-the-drc-on-criminal-justice-system/>

In Australia there have been several calls for law reform to end the indefinite detention of people with cognitive and psychiatric impairments, which the Disability Royal Commission's final report cites extensively.

Its recommendations include a review of the Law, Crime and Community Safety Council (now the Standing Council of Attorneys-General) National Statement of Principles Relating to Persons Unfit to Plead or Found Not Guilty By Reason of Cognitive or Mental Health Impairment (National Principles), which are a non-binding, best practices guide for jurisdictions. They recommend the National Principles be revised with several additions related to making indefinite detention unacceptable (which they currently do not state), plus several recommendations around enabling reasonable adjustments and meeting peoples' support needs.²⁸

We strongly urge the Department to closely examine these recommendations and align the Strategy with them.

For the National Autism Strategy to create the change we need to ensure an inclusive life for all autistic Australians, it must address the harms caused by the justice system. Without critically examining and meaningfully addressing the evidence gleaned by the Disability Royal Commission of the overrepresentation of people with complex needs in the criminal justice system—and by including the experiences and views of those with lived experience of the justice system—we are concerned that autistic people with an intellectual disability will continue to experience a justice system which does not deliver justice on an equal basis with others, but instead perpetuates severe human rights breaches.²⁹

²⁸ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. 2023. Executive Summary: Our vision for an inclusive Australia and Recommendations. Page 130, Recommendation 8.12. <https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Executive%20Summary%2C%20Our%20vision%20for%20an%20inclusive%20Australia%20and%20Recommendations.pdf>

²⁹ See, for example, the evidence about the treatment of two First Nations people, 'Winmartie' and 'Melanie', who were found unfit to stand trial. They were detained in forensic facilities in the Northern Territory and New South Wales, respectively, and subjected to restrictive practices including long-term seclusion, and in Winmartie's case, chemical restraint. Both of their experiences show how some people with disability (in these cases, intellectual disability and other complex needs) "remain in detention beyond the period they would have served in prison had they been convicted of the criminal offences for which they were initially charged". The evidence from that public hearing also showed how without proper support and treatment, a person found unfit for trial are at far greater risk of human rights abuses. See: Public hearing 11: the experiences of people with cognitive disability in the criminal justice system. 2021. <https://disability.royalcommission.gov.au/public-hearings/public-hearing-11>

5. Include a focus on positive behaviour support and reducing restrictive practices

The Strategy must include an evidence-based understanding of restrictive practices and behaviour support and shape its subsequent actions based on lived experience.

The Discussion Paper mentions what it has heard from inquiries and consultations regarding the experiences of restrictive practices, including in which settings they are more likely to occur and the impact of ‘behaviours of concern’.

However, we are concerned there are significant gaps at the moment. The Discussion Paper and the consultation process have not sufficiently explored the current evidence base about restrictive practices, and there has not yet been meaningful engagement with the community about the behaviour support needs of autistic people with an intellectual disability.

For example, the Discussion Paper says “restrictive practices can be used across Australia, as a last resort, to prevent or protect people from harm. This includes a perceived risk of harm. This may include preventing or protecting an individual or others from ... ‘behaviours of concern’”.³⁰ This is too narrow an account of the use of restrictive practices in Australia as it does not accurately reflect the relevant legislative context.

That context is undeniably complex, as the regulation of restrictive practices in Australia primarily arises under state and territory disability services and mental health legislation and a range of other policy directives. As the Disability Royal Commission’s final report recognised, there is currently significant inconsistency in the regulation of restrictive practices across jurisdictions. This is also something the Strategy should take into account and target actions to address.

It is useful, however, to consider the legislative context set by the *NDIS Act 2013*, which considers Australia’s international human rights obligations under the UNCRPD. Given that restrictive practices can present serious human rights breaches—and there is a lot of national and international evidence to suggest that people with an intellectual disability are most at risk of restrictive practices³¹—the legislative setting stipulates **the reduction and elimination of restrictive practices**. The Strategy must commit to a pathway to eliminating the use of restrictive practices, which has been agreed by Australian Governments since 2014,³² and shape its actions around it.

As we have previously discussed, people with complex support needs are most likely to experience restrictive practices, and these are likely to occur in closed settings such as group homes. It is therefore crucial that the Strategy consultation process includes meaningful engagement with people with relevant lived experience and their family members or other supporters. Consideration should also be

³⁰ Page 18 of National Autism Strategy Discussion Paper.

³¹ Clark, L.L., Hext, G. and Xyrichis, A. (2018), “Beyond restraint: raising awareness of restrictive practices in acute care settings”, *International Journal of Nursing Studies*, Vol. 86, doi:10.1016/j.ijnurstu.2018.06.006.

³² National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector, 2014. <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-framework-for-reducing-and-eliminating-the-use-of-restrictive-practices-in-the-disability-service-sector>

given to the body of evidence developed for the Disability Royal Commission, including two dedicated research reports.³³

Doing so will also allow the Strategy to shape actions that are informed by lived experience and sufficiently targeted to increase access to person-centred, evidence-based behaviour supports that are fit-for-purpose and reflect Australia's international human rights obligations.

³³ Cortis, N., Smyth, C. and Katz, I. (2023). *Reducing restrictive practices: A review of evidence-based alternatives*. Report for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Sydney: UNSW Social Policy Research Centre. <https://disability.royalcommission.gov.au/publications/reducing-restrictive-practices-review-evidence-based-alternatives>; Spivakovsky, C., Steele, L. and Wadiwel, D. (2023). *Restrictive practices: A pathway to elimination*. Report for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. <https://disability.royalcommission.gov.au/publications/restrictive-practices-pathway-elimination>.

6. Address mental health barriers faced by autistic people with an intellectual disability

Ensure the Strategy includes targeted and sustainably funded actions to address mental health barriers experienced by autistic people with an intellectual disability, especially in relation to diagnostic overshadowing.

Like autistic people, people with an intellectual disability experience substantially higher rates of mental health conditions and significantly lower rates of preventative healthcare compared with the general population.³⁴ At the same time, there is a lack of recognition in current mental health and disability policy that people with intellectual disability as a group are at high risk of experiencing mental ill-health.³⁵

As a result, people with intellectual disability—as has also been found for people with autism—who experience mental ill-health face major barriers in access to mental health services and treatments, compounded by what researchers have called an “impoverished service system” characterised by poor cross-sector coordination and a lack of preparedness of staff to meet individual’s support needs.³⁶ These issues are compounded for autistic people with an intellectual disability.

Diagnostic overshadowing is also a significant barrier for autistic 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.³⁷ This is a critical consequence of stigma and discrimination that we know contributes to the shorter life expectancy and high rates of preventable deaths of people with an intellectual disability, including autistic people with an intellectual disability.

We strongly recommend the Strategy includes targeted and sustainably funded actions to address the mental health barriers experienced by autistic people with an intellectual disability. It should include specific measures focussed on eliminating diagnostic overshadowing and better training mental health professionals to accurately assess autistic people with intellectual disability in a person- and family-centred, evidence-based way.

³⁴ Department of Health (July 2021). *National Roadmap for Improving the Health of People with Disability*. <https://www.health.gov.au/sites/default/files/documents/2021/08/national-roadmap-for-improving-the-health-of-people-with-intellectual-disability.pdf>

³⁵ 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

³⁶ J. Troller. (2014). Making mental health services accessible to people with an intellectual disability. *Australian and New Zealand Journal of Psychiatry*, 48(5): 395.

³⁷ 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.

7. Include supported decision making and support the development of natural safeguards

The Strategy must include targeted actions and significant investment in independent resources for capacity building to increase social and economic inclusion as well as natural safeguards in the lives of autistic people with an intellectual disability, especially access to supported decision-making.

The Discussion Paper includes a range of important issues heard by the consultation process around social and economic inclusion; diagnosis, services and supports; and health and mental health. Each theme includes several important experiences of autistic Australians which will shape the Strategy.

We are concerned that supported decision-making is not mentioned at all, given its relevance to each of these themes.

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, i.e., supported decision-making.

As we have argued in previous submissions,³⁸ a significant investment in targeted programs that 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 for 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.³⁹

It tends to be a less well-developed concept in terms of support for autistic people. As such, engaging directly with autistic people with an intellectual disability and their families or other supporters about how the Strategy can include specific measures to enable greater access to 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. They would have the most to contribute to the development of the Strategy in this regard.

We ask the Department to engage meaningfully with autistic people with an intellectual disability and their families or other supporters to ensure the Strategy includes a range of specific actions to increase

³⁸ Inclusion Australia. (2021). Submission to the NDIA on Support for Decision Making.

<https://www.inclusionaustralia.org.au/submission/submission-to-the-ndia-on-support-for-decision-making/>;
Inclusion Australia (2023). Submission to the Disability Royal Commission on Guardianship and Substituted Decision Making. <https://www.inclusionaustralia.org.au/submission/submission-to-the-disability-royal-commission-on-guardianship-and-substituted-decision-making/>

³⁹ 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>.

access to supported decision-making for autistic people. We believe this can be achieved especially through significant investment in independent resources to build capacity to implement evidence-based supported decision-making practices, especially in closed settings such as group homes or in the justice system.

Apart from being a fundamental human right, there is a growing body of evidence that demonstrates that access to supported decision-making is a highly effective natural safeguard. Supported decision-making also creates and enhances 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 from the Disability Royal Commission explains, 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”.⁴⁰

This evidence must be considered given the glaring findings from the Disability Royal Commission about the increased rates of a range of human rights breaches (including restrictive practices) experienced by people with cognitive impairment and those with complex needs, which is to say many autistic people with an intellectual disability.

This means:

1. We know that supported decision-making is a highly effective natural safeguard, and that people with complex needs tend to have fewer natural safeguards and less opportunity to build those safeguards in their lives.⁴¹
2. We know this group is more likely to live and work in closed settings (i.e. group homes or ADEs) and are therefore at greater risk of experiencing human rights abuses.⁴²
3. It is essential that supported decision-making be a cornerstone of the National Autism Strategy, and that those with the greatest level of expertise are meaningfully consulted in developing targeted and sustainably funded actions to increase access to supported decision-making for all autistic Australians, their families and supporters, as well as the awareness and practice of this fundamental human right in the broader community among educators, health and mental health professionals, government, business, service providers, and beyond.

⁴⁰ Ibid, page 31.

⁴¹ Ibid.

⁴² Ibid.